

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MONICA SUMMERS

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Monica Summers will say as follows:-

1. Introduction

1. My name is Monica Summers. My date of birth is GRO-C 1965 and my address is known to the Inquiry.
2. I am the widow of Paul Summers who was born on GRO-C 1964 and died on 16th December 2008.
3. I now live in Connecticut in the USA, but met Paul in Plymouth, England in September of 1986. During that time, I was an exchange student and Paul was a first year Architecture student. The top two floors of the School of Architecture building were used for exchange students and some first year students as well.

2. How Affected

1. I met Paul on my first day at the college. He was very striking, he was six foot four inches tall and very attractive. We became friends but it was not until May of 1987 that we started dating.
2. About half way through the academic year of 1987, I discovered Paul was a haemophiliac. In July 1987, I left the UK, but Paul and I stayed in contact via letter and phone. We met up again in March 1988 when Paul flew from Chicago to Boston at the end of his university field trip.
3. From March until August 1988, we continued to communicate through letters and the occasional phone call. After I had seen Paul in Boston I realised I was in love with him.
4. To look at Paul no one would have had the slightest clue about his health. He liked to jog and did so for many years until repeated bleeds in his knees put a stop to his running. He also enjoyed playing squash, badminton and backyard cricket. As a proud Welshman he was a huge rugby fan along with Welsh football and supported Cardiff City together with Arsenal.
5. In August 1988, Paul flew out to visit me in America. I was delighted when he said he wanted to come to visit for three weeks. Shortly after his arrival, however, I sensed something was a little off. After about a week he told me why he had come. I can still clearly hear and feel how his words changed my life from that moment and have continued to do so to present. I was absolutely devastated that my handsome, kind, gentle, talented man had become infected with this horrible virus.
6. I will come back to comment on the impact later in the statement.
7. I would indicate that Paul's haemophilia was relatively mild. He would go months and months without suffering a bleed.

8. I know when he was based in Cardiff he was under the care of a Professor Bloom from a young boy until his mid twenties.
9. Paul suffered with significant nosebleeds, which would often last 10 hours plus with no let up. He could be stubborn at times and when it came to nosebleeds he did anything and everything he could think of to stop them on his own because he did not want to go into the hospital.
10. Paul suffered with hay fever, which increased the chances of nosebleeds and he also experienced bleeds to his knees, hips and later in his life he was diagnosed with gallstones. Often he would have severe stomach pains and vomiting with very little warning.
11. These attacks would not only physically wipe Paul out but would also weaken him as well.
12. Exhibited before me at Exhibit WITN2560002 is a letter dated 18th September 1986, from Dr P. Greedharry (Clinical Assistant to Professor Bloom) to Dr Stafford at Plymouth General Hospital which states Paul was Hepatitis B(C) antibody positive and he was HTLV-III antibody positive. I refer to Exhibit WITN2560002. The letter indicates that he had not so far suffered from any symptoms of any AIDS related complex. Paul found out he was HIV positive in November 1986 in Plymouth.
13. The letter states Paul was moving to Plymouth to attend the Plymouth Polytechnic and asks Plymouth Hospital to kindly look after him for the Haemophilia Centre, Cardiff while he is there.
14. Despite the fact the letter indicated he was HTLV-III antibody positive there was no notification to Paul of this fact nor was he provided with any counselling. Exhibit WITN2560003 is a letter dated 1st December 1986 from Professor Bloom to Dr Prentice, a Consultant Haematologist which states that Paul was 'Counselled extensively' which is not true.

15. When Paul was in Plymouth the doctor who was looking after him did test him for HIV and it came back negative. I remember this clearly because one night at about 10:30 Paul came up to my floor in the Hoe Centre where we were living in Plymouth and asked if I wanted to go to the pub. I remember he was in high spirits. Years later he told me he had found out earlier that day back in 1987 his HIV test results came back negative, but when tested again he was positive. I'm pretty sure the repeat test was done in the spring of 1987 when the result came back positive. When Paul found out he did not tell his parents because they were going away to Spain for a week's holiday and he did not want to ruin it for them.

3. Other infections

1. When we were on holiday in Jersey in the summer of 2005, I can recall Paul carrying our daughter, Tia-May up a steep hill from the beach. When he got to the top of the hill he was completely out of breath and was really struggling.
2. I drove the car back to our hotel and when we returned home Paul visited the Haemophilia Centre to explain what had happened. Tests were run and Paul was diagnosed with portal pulmonary hypertension and later a scan revealed a tumour on his liver. This was absolutely shattering news for us.
3. Paul was seen by a liver specialist in the Heath Hospital in Cardiff and also by a specialist in London. He was then referred to the Liver Transplant Unit at the Queen Elizabeth Hospital in Birmingham.

4. Consent

1. I would say Paul was very likely to have been tested without his consent. Suspicions began to arise before he "officially" received his HIV diagnosis. Prior to his positive status Paul would go about once a month to the Haemophilia Centre in Cardiff for a check up and to have his blood drawn. The doctor asked him a few times 'did he have a girlfriend?' Or if he 'needed any condoms?' This makes me think at the least the Haemophilia Centre knew something was

seriously wrong with Paul and at the most that he was HIV positive for them to ask these type of questions.

2. I know in much later years Paul's test results were quoted for the purposes of research; this is due to the fact that a doctor who used to work at the Heath Hospital stated that he would refer to Paul in conferences as Mr X. The doctor who told Paul this took great pride in being able to work with someone like Paul. Paul had a very good rapport with this doctor and always felt the doctor was treating the "whole" person and not just the symptoms. Paul never felt rushed and he always felt taken care of. We felt positive about the research the doctor was doing.

5. Impact

1. I feel that it is important to set out the history of my relationship with Paul and the impact that his infection has had upon me and upon our relationship.
2. In terms of our relationship, it moved on and it was planned for me to travel to Wales in December 1988 to meet his parents and sister with a view to becoming formally engaged.
3. I stayed from 22nd December 1988 through to early January 1989. I was able to see Paul in Easter of 1989 for a week and then I returned for good in early July 1989.
4. Paul earned a First Class Honours degree in Architecture and in September of 1989 Paul was offered a job in Bristol. Paul went to stay with some Plymouth classmates who were also in Bristol during the week and he would then travel back to Wales on the weekends to be with me. I was living with Paul's parents.
5. We subsequently had a civil wedding ceremony in Cardiff on 3rd November 1989 so that I could stay and work in the UK. At that point I moved to Bristol and Paul and I along with three Plymouth classmates were renting a house in Cotham,

Bristol. We bought a one bedroom flat in Clifton in April 1990 and flew back to the States to be married on 20th April 1990.

6. At the time of our wedding, Connecticut State law required a blood test for both bride and groom before obtaining a marriage licence there. This test was to see if either party had Sexually Transmitted Diseases ('STDs'), amongst other things. I was beside myself with worry due to Paul being HIV positive. I had to confide in my best friend and I asked her to find out exactly what the test was for. Thankfully they did not test for HIV and we were able to proceed with the wedding. Additionally, at this point, my parents were unaware of Paul's HIV status although they did know he was a haemophiliac. It was not until almost seven years later that we told my parents the truth about Paul's health. It was very difficult keeping that from my parents.
7. We flew to Florida for our honeymoon and during the honeymoon Paul suffered several nosebleeds. I recall one of them being so bad he had to leave our table and was in the men's room for the entire meal. The waiter went to check on him and I remember being an absolute wreck wondering if he was all right.
8. We returned to Bristol in early May of 1990 it was during this time Paul was diagnosed with cirrhosis of the liver. Paul always enjoyed a pint or two a glass of wine or champagne but nothing heavy. When he was diagnosed with cirrhosis he stopped drinking completely.
9. After working for a few years Paul returned to study for his Masters in Architecture, back in Plymouth and I became the sole breadwinner. I would work during the week and then travel to Plymouth to see him on weekends.
10. Paul successfully completed his Masters Degree in Architecture, however, it was during the time of the recession and employment was very difficult. We therefore rented out our flat and moved back to Wales to live with Paul's parents. We subsequently found jobs back in Cardiff.

11. Around this time he also started receiving triple therapy treatment for his HIV status. During the first combination of triple therapy, some of the tablets were so large we had to break them up into smaller pieces so Paul could comfortably swallow them. The process could take up to twenty to thirty minutes at times. I can remember one of the combinations he received caused a very painful raised rash over his entire body, including his tongue. Despite the pain and discomfort Paul was going through, he continued to work full time and never wanted to be treated any differently because of the fact that he was a haemophiliac.
12. The awareness of HIV and AIDS was growing in the press and therefore the less Paul wanted to share that he was a haemophiliac with people he met especially employers.
13. I was always thinking of ways to keep him safe, not just healthy, but how to protect him from unwanted questions about his health should they arise.
14. Paul worked at several different practices in South Wales, but then decided he needed to move to London to gain the experience in order to further his career. As a result, we were again separated.
15. I fully appreciate that many couples live apart due to work or careers. However, I would like to emphasize because of Paul's diagnosis I lived in a high state of alert and stress, fearing for the person I loved so deeply and fearing the unknown of not being there when he may have needed me.
16. There was constant fear Paul may get a cold, which could develop into something more serious and result in him being admitted to hospital. That was pretty much how I thought and felt for more than 20 years whether I was with Paul or not. The high level of stress and anxiety became my normal and all that I knew. Over the years it has taken its toll on me physically, mentally and emotionally and to some degree continues to do so.
17. I knew that moving to London was what Paul really wanted to do and therefore I supported this although at times it was very hard on our marriage.

18. I was still living with Paul's parents and we would alternate our weekends between London and Wales.
19. For his first Christmas in London we decided we would fly back to the States to spend it with my family. The preparations for trips back to the United States were very stressful. We had to make sure we had the correct letters from his doctors stating he was a mild haemophiliac; and that we were carrying Factor VIII in case he had to treat himself; and then there was the worry of having to pack Paul's medication. We also had to make sure we had travel insurance.
20. We also never dared to declare his HIV status when travelling back to the States as we had heard so many horror stories of men who were being awfully treated as a result. On a few occasions I even sent his medication in the mail so we did not have to worry about the stress of bringing it with us on the plane. Thankfully we were never questioned, although I recall on one occasion our suitcase being pulled for a random search and I can remember the anxiety we both felt.
21. We arrived in the United States on 23rd December 2001. The following day we went with my younger sister to do some last minute shopping. We were in a record store, I was at the front of the store when I heard my sister screaming my name from the back of the store.
22. I ran to the back of the store and Paul had passed out and had fallen face first into a huge CD display. He was totally disorientated and couldn't recognise who I was. His face was bloody and he was shaking like he was having a seizure. I was absolutely terrified.
23. Medics were called and he was taken into hospital. He suffered two black eyes, a fractured jaw and was covered in bruises. I can remember again the anxiety I experienced, not only with seeing him injured, but also with my concerns about paramedics treating him because of his HIV status.

24. I remember thinking the paramedics need to wear gloves and the high anxiety I experienced.
25. When we returned home to Wales, Paul went to the Heath Hospital in Cardiff to have various tests. The doctors treating Paul could not find a reason for the passing out episode he experienced but decided to prescribe him beta-blockers.
26. He suffered tremendously negative side effects. He would have difficulty speaking, forming words, he would sweat and experienced heart palpitations. He said during an episode it was like being paralysed.
27. It happened again in Cardiff before returning to work in London, but this time Paul could sense he was going to pass out and managed to sit down. He would avoid certain retail stores because the florescent lights made him anxious and feel like he might pass out.
28. I remember one particular incident when we were walking down Queen Street in Cardiff after work. We were heading towards our car and an episode came on him very quickly. I recognised all of the signs and did my best to comfort him as he was getting not only anxious, but frightened as well. Thankfully we made it safely to the car and I drove him to the Heath Hospital. When I told him we were going to the Heath he became very upset and begged me not to take him there. I can remember him saying to me 'is it because I did something wrong?'
29. As I got to the hospital he was just starting to come out of the episode. He did agree to go into the hospital and we managed to get him up on to a ward; avoiding A&E. We were able to explain the experience and previous experiences Paul had suffered.
30. I recall one particular occasion when he said to me 'Mons I am the one with the question mark over my head'. I will never forget that comment. I also recall him telling me he never thought he would get married or be a father and I am so thankful that he achieved both of those dreams.

31. Due to Paul's health, it was not possible for us to have children of our own. We went to a fertility doctor on Harley Street to seek advice as to what options might be open to us; particularly in terms of sperm washing, although that never came to anything.
32. We ended up trying the IVF route with a sperm donor. We paid privately for those IVF treatments, but unfortunately each one was unsuccessful.
33. That in itself caused a huge amount of stress and anxiety for us and it was compounded when one day on my commute in to work I recall hearing on the radio the fertility doctor we had been seeing in Cardiff had been asked to resign because it was discovered he was falsifying his success rate.
34. After a few years we began to talk about adoption and went through the lengthy application process. The process itself was extremely harrowing, but ultimately we were successful and our daughter, Tia-May, came to live with us on 16th December 2004.
35. We were actually, the first applicants in the Vale of Glamorgan with our circumstances to successfully adopt a child.

6. Treatment/Care Support

1. I would stress that Paul had always maintained a monthly routine check up at the Haemophilia Centre in Cardiff and when we moved to Bristol he did exactly the same at the Bristol Royal Infirmary.
2. As well as being HIV positive, Paul was also prescribed interferon for Hep C. When he was prescribed the interferon he was advised to stay off work for about three to four weeks because of the flu like side effects.
3. During those initial weeks the side effects were relatively mild. However, after Paul returned to work, the side effects started to escalate. Paul was achy, run down and had trouble sleeping. As he had already been signed off from work for

several weeks there was absolutely no way he would take more time off so he simply battled through.

4. He always attended his monthly appointment at the Haemophilia Centre, however, at times the appointments caused him stress as he would try and arrange them to fit near or during his lunch hour so he did not miss work. However, they would often overrun and he would always be extremely concerned about making up time in work; either by working through lunch the following day, going in early, staying late or sometimes all three.
5. In the spring of 2008, Paul had a week's assessment at the Queen Elizabeth Hospital, Birmingham. Again this was extremely difficult time for us. They would only accept patients who had a minimum of five years survival. Paul passed the assessment and was placed on the waiting list for a liver. From that point onwards, anything approaching normality that we had in our lives ceased to exist. We were both extremely anxious a phone call could come in at any time of day or night and we would need to be at the hospital within a three hour window.
6. Our cell phones were always charged and within earshot and if we went somewhere new we were constantly checking to make sure there was a strong signal and good reception. It was both stressful and exhausting. We had two phone calls and each time we packed up and drove to Birmingham in the middle of the night. Unfortunately on each occasion we were told the liver was not right.
7. On the third occasion, the call came on 8th December 2008 and we quickly made our way to Birmingham. I recall Paul insisted we stop at our friend, Vicky's house, to drop off her iPod. Paul had put together a party playlist for her 40th birthday later that month and he desperately wanted her to have it.
8. Paul was scheduled for surgery the following morning and I remember being positive and thinking the surgery would give us our life back. I can recall after about 45 minutes, the Social Worker came to find me. She told me the surgeon wanted to speak with me. I was beside myself with worry. He indicated Paul was out, but they had not started the surgery yet because what was originally called

'mild to moderate' portal pulmonary hypertension was in fact now severe and he said that 'if we do not proceed with the surgery I don't know if Paul's body is strong enough to bring him out of the anaesthesia and if we do proceed with the surgery I do not know if Paul is strong enough to survive'.

9. I was absolutely devastated and the situation was horrendous beyond words. We had not talked about the 'what if' because no one, either medical or otherwise, had given us any indication the surgery would be anything, but successful.
10. The transplant did, in fact, proceed and Paul survived, however he took a long time coming around and his blood pressure was exceptionally high.
11. His blood pressure would lower slightly when I sat there and held his hand. He eventually came around and was able to say 'hi' which was the only and last word he spoke. Eventually they were able to remove the breathing tube and use an oxygen mask, but it was very tight to his face and caused bruising to his forehead. He would wake for very short periods and he could understand what was being said to him and he would reply by nodding or shaking his head.
12. At about 1.00am on 16th December Paul's nurse telephoned me and said I needed to come over straight away. She said, 'Paul's not doing very well'. I ran as fast as I could to get to his ward. I was met by the nurse and the doctor on duty and was told Paul's heart rate was very high and that they were trying various methods to get it down. I recall saying 'he will be concerned to see me over here at this time of night and he will know something is wrong'. Their reply was 'he already knows'. I was able to see him briefly and they told him they would have to intubate him again. He shook his head to say No. I said to him that 'we have been through many bumpy patches before' and I asked him if he wanted to see a picture of our daughter, which I had on my phone. He shook his head No.
13. I went to the waiting room until they returned to get me. It was probably some thirty or so minutes later when they returned to tell me they had shocked Paul's

heart at least twenty times, but could not get a normal rhythm and they had to stop.

14. A priest was called and he gave Paul the last rites. My in laws were in Wales. They dropped Tia off at our friend Vicky's house and then drove up to Birmingham. My sister in law was staying close by and was able to come quickly. The four of us were around Paul's hospital bed when he died at about 6.30am on 16th December 2008.
15. After he died I asked to be alone with him and can remember stroking his face, touching his hair and hands and I even pulled the sheets back to look at his feet. I remember studying him so that I could commit everything about him to memory.
16. After leaving the hospital later on the morning of Paul's death I went back to Paul's aunt's home where I showered tried to eat some thing and then began the arduous task of making his funeral arrangements. I did not want to wait until the New Year and was able to arrange his funeral for the 24th December. I arrived home early evening on the 16th December. Tia was home with our friend Vicky and her husband. Telling my five-year-old daughter that her daddy was not coming home ever was beyond difficult. She was physically sick after I told her and again the following morning. The days leading up to Paul's funeral were a haze, yet I was in charge of making all the decisions. I wrote the death announcement and Paul's eulogy and arranged pallbearers. I asked Paul's boss Gareth if he would read the eulogy I had written. His funeral was held on 24th December and it was a beautiful tribute to Paul with family, friends and colleagues. Some travelling from the United States and Switzerland to attend.
17. The days, weeks and months that followed were more than I could bear. I was a 43-year-old widow with a five-year-old daughter. Getting Tia to school as well as food shopping were all that I could manage on some days. I could not return to my part time job and everyday for almost two years my daughter would ask 'mummy when is daddy coming home'. Sometimes she would ask several times

a day and I answered every time as gently as I could, but it was very emotionally draining. To this very day, Tia still says she wishes daddy didn't have to die.

18. Paul did not make choices that resulted in him becoming HIV positive, or developing sclerosis of the liver resulting in a cancerous tumour which led to needing a liver transplant.

19. In October 2009 we moved back to Connecticut as I wanted Tia to grow up with cousins around her. I can only speak for myself and my daughter as to how we have been impacted by Paul's death. Over the last ten years both myself and Tia have been through many changes. Making big life decisions on my own has been tough. In 2014 my daughter was diagnosed with High Functioning Autism and ADHD. She has anxiety and struggles with forming relationships. This diagnosis compounds her ability to process Paul's death. As a result of Tia's diagnosis she has been prescribed a low dose of medications to help her anxiety and her ADHA diagnosis.

20. In addition to the grief, I have genuine concerns and worries regarding our future. My daughter has two more years of high school before transitioning to some type of higher education. I have concerns about saving for college, saving for her future and mine. Being able to travel back to Wales so Tia can visit her grandparents and her aunt and having financial security now and in the future for the both of us.

21. Paul was the main breadwinner and we had a plan for our future and our retirement. All of that has been taken away.

22. I have experienced grief before having lost all my grandparents when I was still in my early twenties and in 2000 my father passed away at the age of 64yrs. I am not sure I will ever fully accept Paul's death. I am now living a life without my husband, partner or the father of my child because of decisions made by others regarding Paul's health.

7. Financial Assistance

1. Since Paul's death I have lived on a budget and it has been extremely difficult to the point of having to borrow money from my family and on occasion using my credit card to pay some medical bills.
2. Up until November of 2017 I did not work for several reasons, the main one being The MacFarlane Trust had rules about deducting money from the monthly grant if I worked. The other reason has to do with my daughter's various doctor and therapy appointments making it difficult to maintain a part time job. The part time job I did have in 2017 was short lived for the reasons previously stated.
3. I confirm we did receive what the Macfarlane Trust liked to term 'discretionary grant', however I always found them extremely difficult to deal with. Over the years it became more and more difficult to obtain money from the Trust and there were numerous hurdles to overcome before they would pay anything. For example, they would often change the rules of the scheme without prior notification.
4. On one occasion my Widow's Parents Allowance (WPA) was increased slightly by a few pounds and yet the payment from the Macfarlane Trust was reduced some £80 or so because I went over some threshold. My WPA was considered income, however, the Trust did not consider the Child Benefit Allowance as income.
5. I know that Paul did receive some money from the Government which was distributed with the help of Meade King Solicitors. This was in approximately 1990 and I believe it was in the sum of £32,000. I may be able to confirm that figure but at the present moment I can't be 100 per cent sure it was the exact amount.
6. This money was something that we felt we had to take, as it was a settlement for all of those infected.

7. The McFarlane Trust made its final monthly payment of £1,333 on the 13th October 2017 and on 16th November 2017 I, along with other Welsh widows, received a one off lump sum payment from the Velindre Trust. Since the November 2017 payment I have not received any additional financial support from the UK.

8. **Other Issues**

1. The grief has not only been emotionally exhausting, but physically painful. I can remember occasions when I have desperately wanted to step out of my own skin because I ached so much from the loss of my husband.
2. Despite everything my husband was extremely positive and for the vast majority of our life together he did not complain or blame. However, I believe a lot needs to be answered for.
3. Paul along with all the infected haemophiliac victims – they did not knowingly inject themselves with contaminated blood products. They and their parents TRUSTED in the NHS senior medical staff who were making life altering decision for these sons, fathers, brothers, uncles, and grandfathers. The families and their dependents of all the victims continue to be negatively impacted by those “decisions“ made thirty plus years ago.
4. The Public Health Care System knowingly failed to protect those vulnerable individuals. It now falls to the remaining survivors, widows and their dependents to pursue not only the truth of what happened, but also justice for all those who lost their lives and for all those who continue to suffer.

Statement of Truth

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

Signed

GRO-C

Dated

20th March 2019