

Witness Name: Anthony Summers  
Statement No: WITN2406001  
Dated: 1<sup>st</sup> January 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF ANTHONY SUMMERS

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

I, Michael Anthony Summers make this statement true to the best of my knowledge and belief and will say as follows:-

1. **Introduction**

1. I would confirm that I am retired although I now work part-time for Llandough Hospital as a Mental Health Manager. My position is that I am married and my Wife's name is Patricia Summers.

2. We also have a daughter Bethan Summers and we had a son Paul Summers who is the subject of this statement. Paul's date of birth is the GRO-C 1964.

## 2. How Affected

1. I would confirm that I nor any other members of the family suffer with haemophilia however my son Paul suffered with haemophilia.
2. At the age of around 5 he was diagnosed as suffering with haemophilia, he had haemophilia A. He was categorised as a moderate to severe haemophiliac. In terms of background, Paul used to have quite bad bruising and if he suffered any cuts then the bleeding would take quite a while to stop.
3. As a youngster we were frequently taking him to Bridgend General Hospital. When we attended Bridgend General Hospital he was treated on an orthopaedic ward and adult ward, however, at that time he was not treated as having haemophilia. This often meant the treatment wasn't right for him and that he had, for example, traction on one occasion to pull his joints apart.
4. When he was about 4, I can recall that he fell off his bike and we took him to Bridgend General Hospital. It was a simple fall, there were no fractures but he had extensive bruising and swelling in his joints. I remember him being in Bridgend General Hospital for three weeks.

5. As luck would have it a visiting Doctor from Cardiff Royal Infirmary attended and noticed that Paul had been on the ward numerous times. As a result he ordered a blood test on the Wednesday and I recall on the Friday he phoned my wife and myself to get to the Hospital as Paul had been diagnosed with a severe blood disorder.
6. When my Wife and I arrived at Bridgend General Hospital an ambulance was waiting and Paul was taken to the Cardiff Royal Infirmary where he met and came under the care of Professor Bloom.
7. My Wife and I were horrified at what we discovered but we were reassured that Paul could have a normal life with the right treatment. We were making regular visits to the Infirmary and then at 12-18 months after that to the Haemophilia Centre which had been opened at the newly built Heath Hospital in Cardiff. For a period of time then Paul had both reactive treatments and some prophylactic treatment.
8. Between the ages of 6 to 11 he had less visits to Hospital and was fortunate that he didn't have many bumps that required treatment. From the age of about 11 onwards he was beginning to grow and indeed he subsequently grew to 6 foot 4 inches.
9. I can recall him leading a fairly normal life and on one occasions going skiing with the school in Italy. We agreed for him to go and he took all his medical cards with him etc. I can recall when he came back we watched the plane land at Cardiff Airport and I remember an Ambulance going out to the plane. I

assumed that was for Paul but fortunately he had got through the trip unscathed.

10. At about the age of 14 or 15, Paul was then taught how to treat himself at home. This was good and improved his quality of life but we were never told of any options for Paul to attend Hospital for treatment and it was at this point he began to use factor 8. These were the products I am sure were contaminated and I am sure that it would have been around this time that Paul became infected with contaminated blood.

11. I can recall at the time some comment being made about the factor 8 being cost effective. I didn't take it any further and just accepted that this was appropriate treatment for my son.

12. Prior to that Paul would have maybe two blood transfusions a year and they were from what I would describe as ordinary blood products rather than the Factor 8. The biggest problems that Paul had were his hips and knees which caused internal bleeding. From the age of 14 or so he began treating at home and would store the blood products in a fridge.

13. Paul then went to College at Bristol Polytechnic to study Civil Engineering and would have had some treatment at the Bristol Royal Infirmary. Paul didn't particularly enjoy his course and didn't feel that Civil Engineering was for him and therefore he dropped out. He started doing some sketching for an architect in Dinas Powys and I actually went to see them, they suggested that

Paul should do some A-levels which he did and they then helped him to do a degree in architecture at Plymouth Polytechnic.

14. As indicated he had already had some brief involvement with Bristol Royal Infirmary and I can recall him going there for two visits but it wasn't for anything major. I have since looked at the records from that time period and there were no causes for concern between Bristol Royal Infirmary and the Heath Hospital Cardiff.

15. When he arrived at Plymouth things began to change. In correspondence between Plymouth and the Heath Hospital in the records that I have seen then Plymouth used HTL which was phraseology for HIV and that was used between 1985 to 1987.

16. There was even mention of this in 1984 to our own General Practitioner. It was Derriford Hospital in Plymouth who were treating him and I know from the records that they were pretty certain that Paul was HIV positive. In October 1985, they were convinced that the initial blood test was positive and then 10 days later they did another test which was negative. Obviously, at that point we were relieved but a third test was commissioned and this showed that he had HIV positive. This would have been in Paul's first year in Plymouth when he was studying Architecture.

17. I can recall that day I was working in Swindon and I had a call from Paul to go down for the blood test with him. After he was told he was HIV positive, he

was offered some counselling but felt he didn't need that and the reaction of both of us at that stage was initially, 'what do we do now?'

18. I can recall Paul attempting to make light of the situation with him saying what he could really do with was a couple of pairs of jeans and we went off shopping for him to buy a steak. When I look back over the records now I have concerns regarding the treatment at the Heath Hospital and the lack of information that we were provided with by the Heath Hospital.

19. There have been issues throughout the period of time when he was treated at the Heath Hospital, one instance was when he was taking medication to fight off hepatitis c and his liver function changed. I can recall us being told by Professor Bloom's department that he was doing as well as expected. We were never ever told that he had hepatitis C and were totally unaware of that until he began treatment at Plymouth Hospital who were far more open about what was going on with him. It seems clear now that the Heath were aware of the hepatitis C and HIV but we were never told about it by the Heath nor was Paul ever told about it there. We were told at Plymouth hospital.

20. At that point in time it is worth bringing into context that Professor Bloom is very well respected and indeed he was known to be very good in terms of his treatment with haemophiliacs. However as a result of that respect there was really no questioning of him or challenging of his expertise.

### 3. Other Infections

1. Paul experienced hypertension due to the drugs he had to take for his hepatitis C. My son required a liver transplant in 2008 as a result of liver problems as a result of hepatitis C.

### 4. Consent

1. I would confirm that I believe that various blood tests were carried out by the Heath Hospital in Cardiff and the results of those were never made known.
2. I do not believe that the results of these tests were ever properly explained to Paul nor was his consent properly taken.

### 5. Impact

1. In terms of the impact then I would confirm from a personal point of view that after October 1985 when Paul was diagnosed I became deeply involved with creating noise about what was happening to Paul and to fellow haemophiliacs.
2. I made a lot of noise about failure to treat appropriately and over the years I have lost count of the number of times I have been to Westminster to lobby MP's and to watch debates and try and do as much as I possibly could.

3. I haven't made it a crusade as such that I wanted Paul to lead a normal life which he managed to do until the last 10 years of his life. In terms of the impact when Paul was diagnosed, it was a huge impact for us all. I would describe it as being a fear in terms of a fear of what the future held for Paul and also fear over the fact that Paul himself wanted anonymity and therefore it was only myself, my wife and my daughter who knew that he was HIV.
4. We became very evasive in giving answers to close relatives and Paul didn't join any of the haemophilic action groups or anything of that nature as he very much wanted to keep a low profile.
5. After the HIV diagnosis for the next 12 months or so Paul had some visits to hospital but was never hospitalised as such. He was able to self treat and he completed his Polytechnic course and actually moved into a shared house out of halls of residence.
6. He was able to self treat and I believe he must have confided in his housemates at that time. Fortunately, Paul obtained a first class degree in architecture and worked initially in Bristol and then in London.
7. In 1990, Paul married his wife Monica Summers and they moved back to live in Bristol and then subsequently he worked in Cardiff. He did a lot of very good work in South Wales and he and Monica were able to adopt a child who was then aged 14 months.

8. It transpired that Monica could not have children although they tried IVF but of course there would have also been issues in terms of the transmission of HIV and hepatitis c. That was a very stressful time for them with lots of tension and trauma for them.
9. Paul's health began to deteriorate 2 ½ to 3 years before his death. I would indicate that a long time before that he had told me about his hypertension. He had been to see a consultant in Bristol and during the tests on his heart the main concerns were expressed about his condition.
10. Obviously Paul's death on 16th December 2008 had a huge impact on us as a family. My wife had suffered with depression and my daughter desperately even now still wants Paul back.
11. As I have indicated in terms of my own position and my fear from the time of diagnosis to what the future would hold and from 2001/2002 could see his health deteriorating such that the hepatitis became a major problem.
12. At the time I had some focus as I was trying to pursue possible claims and to obtain answers and information. I think in some ways that helped me. However, I have over a period of time felt very angry about Paul's death although I am now over that anger. However, in the last two years the guilt has really hit me.

13. I cannot escape the feeling that we should really be asking more questions about the blood products that he was using and about the treatment when he was around the 14 years of age mark. We just accepted what the doctors told us. We should have challenged them and asked, why are you doing this?

14. In reality, I know that probably very little would have changed but I cannot escape the guilt that I feel regarding that. I am desperate to try and obtain some answers to publicise the matter and am desperate to live long enough to see the Inquiry through.

#### 6. Treatment/Care Support

1. In terms of assistance offered then my wife and I have not had any formal counselling offered however when Paul was originally told about the hepatitis he was offered some counselling regarding his sexual life but that was probably not until 1988 and by that stage he had been infected almost four years.

2. I know that in terms of the hepatitis he had some Interferon treatment which was a very debilitating treatment. At that point in time he used to spend a lot of time working from home. He remained a very hard worker throughout his life. Paul was never really secretive with us about his failing health. He kept saying 'there's nothing to worry about'. However, we soon came to terms with the fact that this was not the reality of the matter.

3. By the autumn of 2008 his health had deteriorated so much that he had very significant problems with his liver caused by the hepatitis and also had problems with his heart.
4. He had suffered hypertension as a result of issues with drugs that he was taking for the hepatitis and had to undergo a liver transplant.
5. He was due to have a liver transplant in September 2008 but when he was called to the hospital it was found that the liver was not a good match and the same thing happened in November 2008. Subsequently, on the 8th of December he was called to Queen Elizabeth Hospital Birmingham and he had surgery there for a liver transplant. For the first five days things seemed to be going fairly well but on the 14th of December I can recall being at his bedside and hearing Doctors and the Surgeon talking.
6. I can recall the Surgeon saying that Paul no longer had haemophilia now he had the liver transplant. This was a shock and welcome surprise to me as I wasn't aware that a liver transplant could cure haemophilia.
7. However, I remember two days later the Surgeon saying that they needed to watch his heart rhythms because they were a concern and then on the 16th of December Paul died.

## 7. Financial Assistance

1. In terms of financial assistance then I would confirm that Paul did receive a pay out via the Macfarlane Trust of £25,000.00 and then a subsequent payment after that of £32,000.00.
2. I can recall that we had some help from Social Services for that application and I recall having to attend at a Solicitors office in Bristol to sign for that initial payment to be made. If I had not signed the waiver, I was told that this was not open to negotiation and if I did not sign I may stop others from receiving payments.
3. I would also indicate that the Macfarlane Trust were woeful to deal with. They wouldn't reply to our calls, or advise on what was available to Paul and Monica in financial terms.
4. They were very slow in their responses and in my experience with Haemophilia Wales I have seen them make comments such as "you should teach your potential claimants how to budget".

## 8. Other Issues

1. I really feel, having considered the medical records, that there has been a cover up at the lower level in the Heath Hospital but also at a higher level with MP's and Politicians being involved.

2. I have no doubt from considering the medical records that there is definitely an evasion in correspondence and a real reluctance to release info.
  
3. I would indicate that that policy appears to have changed and that University Hospital Wales have been extremely helpful in terms of ensuring the release of all relevant medical records.
  
4. I would indicate that I enjoy what I do with Haemophilia Wales but when this Inquiry is over I will feel very much as if my job has been done. I am concerned to obtain justice for Paul but also to obtain justice for all the others represented by Haemophilia Wales.
  
5. In terms of summing everything up, I believe that after 30 years of worry, fear, anxiety and guilt, nothing can prepare you for sitting at your son's bed side and watching him die. We all had 20 years of worrying when he had contracted HIV. My family have never understood why this happened, no one should have to prepare for such a loss. He was killed by ill judged decisions.

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

Signed..... **GRO-C**

Dated..... *1<sup>st</sup> January 2019.*