

Witness Name: Patricia Gaynor Summers  
Statement No: WITN2405001  
Dated: 24<sup>th</sup> January 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF PATRICIA GAYNOR 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 Patricia Gaynor Summers make this statement true to the best of my knowledge and belief and will say as follows: -

#### 1. Introduction

1. I would say I am a retired primary school teacher. I am married and my husbands name is Anthony Summers. I have a daughter named 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 my son Paul suffered with haemophilia. He actually had haemophilia A and I would describe him as being a moderate haemophiliac.

2. We did not realise he suffered with haemophilia until he was around 5 years of age. He was an active young man who was often covered in bruises. In hindsight I can recall that when he was around 6 months old he cut his fingers whilst crawling on the floor and I remember tiny spots of blood being all over the floor. I didn't think too much of it at the time but looking back it was heavy bleeding for the nature of the cut.
3. Paul often had pain in his joints particularly his knees and hips and there were a few hospital visits with that. I recall he was admitted to Bridgend Hospital with a nasty injury to his knee. I am not sure how that happened but I know he was in Bridgend Hospital for about 3 weeks. I can recall that he was moved to a men's ward and I also recall a doctor coming around and spotting him on that ward. I didn't actually meet that doctor but I recall a phone call to us saying he was being moved to Cardiff Royal Infirmary and that he had a blood disorder.
4. This blood disorder turned out to be haemophilia. We were assured that Paul could have a normal life with the right treatment and we then made regular visits to the Cardiff Royal Infirmary. After about 12 – 18 months we began attending the Haemophilia Centre at the University Hospital Wales (UHW). Paul then had reactive treatments to any bumps that occurred on his body and he also some prophylactic treatment.
5. We had some visits to the hospital but Paul did live a fairly normal life and I can recall on one occasion him going skiing with the school in Italy. We agreed for him to go and all of his medical cards went with him. I can recall watching the plane land at Cardiff Airport on his return and seeing an ambulance going out to the plane. Both my husband and I had assumed that was for Paul but fortunately he got through the trip unscathed.

6. The treatment until then was fairly unremarkable. Around the age of 14 or 15, I recall that Paul began using Factor 8. It helped greatly with quality of life in that he could treat himself at home. I would confirm that there were never any discussions that I recall about Factor 8 and never any warnings regarding the possibility of blood being contaminated. I didn't raise any issues with the treating Doctors and just took their word that was the way for him to be treated.
7. I can recall that there were some stories in the media about possible contaminated blood and I particularly recall at around the age of 18 there had been talk of infected blood coming from America and potentially drug addicts and convicts supplying blood.
8. It was however at that point all snippets of information and it wasn't something that I ever related to Paul or thought that could ever affect Paul. We had total faith in the treatment that he was receiving and I suppose took the view that the blood came from the NHS and it must therefore be fine.
9. I cannot be certain as to how Paul was actually infected as I assume it was via the Factor 8 products that he used to self medicate with at home. I confirm that Paul went on to Bristol College to study initially and received treatment at Bristol Royal Infirmary. I was not aware of any issues in his treatment there.
10. Paul left Bristol College so no longer needed to visit Bristol Infirmary. After showing a flare for that he then attended Plymouth University and was sponsored by the architect practice that he had been working for.
11. It was my husband Tony who had the most involvement with Paul and his treatment at that point. When Paul was in Plymouth I can recall there was more talk of the contaminated blood and blood products but my view was still that things were blown out of proportion and that Paul

was being well catered for and I simply didn't think that anything would happen to him.

12. I can recall Paul going to an appointment, my husband went with him because I would have been working and it was very difficult for me to get time away from school. It was then that we became aware that Paul was infected with HIV and Hepatitis C ('Hep C'), this would have been in the mid 1990s. I found this very difficult to grasp and to accept. It was difficult because there was nothing to see in terms of any physical appearance and I found it very difficult to deal with. I know that Paul was told that he had HIV in 1986 and diagnosed with Hep C in either 1994/1995.

### **3. Other infections**

1. My son experienced severe problems with his liver as a result of the Hep C and was placed on the liver transplant list.

### **4. Consent**

1. I would confirm that I am aware that various blood tests were carried out by UHW in Cardiff and the result of those were never made known.
2. This would have been after Paul was 18 years old and therefore I would not have had a direct involvement.

### **5. Impact**

1. As can be imagined the infection reports had a huge impact upon myself, my husband Tony and on Paul.
2. I felt a sense of shock and disbelief when Paul was diagnosed with HIV and I remained very sceptical about the publicity that was going on regarding contaminated blood products.

3. I can remember thinking about and trying to rationalise how drug addicts in the US could give blood and how the diseases in that blood could be transferred onto our family.
4. There remained with me a feeling that this didn't happen to us and it was almost a sense of denial. I continued working and Paul was also an extremely private person, he didn't want others to know. It was something therefore that was very much denied. There was not a dramatic and immediate impact upon us save for the initial upset as Paul remained in reasonably good health for quite a number of years.
5. Initially there was no great publicity regarding HIV and therefore it was something of an unknown quantity as to how things were going to pan out at that stage.
6. I would confirm that I have read the statement of my husband Anthony Summers and I agree with that statement.
7. I would indicate that Paul met his wife Monica at University. One of the things that I found quite difficult to accept was the fact that we couldn't have grandchildren with Paul and Monica who would be direct blood relatives.
8. I think there was a mixed reason as to why they could not have children to that namely the fact that they would have had to have undergone IVF due to issues of conceiving but also of course the HIV infection made it almost impossible.
9. Monica and Paul did adopt a lovely daughter Tia-May who we loved and still do love dearly. We have a good relationship with her even though she lives in the US but it was a source of great upset that they were not able to have children naturally.

10. I would confirm that Paul continued to work but there were issues with his health and these increased as time went on. He was not as strong as he had been and I am aware he became tired and would not do as much as he would previously.
11. I can recall some treatments that Paul underwent but he and Monica were a very private couple and we were cautious not to intrude and to upset them.
12. It is fair to say Paul was also the type of person who wanted to protect us and deal with it as he regarded it as his problem and not ours. He did fortunately maintain a good sense of humour throughout.
13. I would confirm that in 2008, Paul's health was failing and therefore he went onto the liver transplant list. I recall him having to go to Birmingham on one occasion for a potential transplant and Tony and I raced up there with them. Unfortunately there was not a match and the operation did not go ahead.
14. On the 8<sup>th</sup> December 2008, Paul of course had a liver transplant operation. My sister lived in Bromsgrove and therefore myself and the family used her property as a base. Paul was in intensive care after the operation, we thought that things would be ok. We were back and forth to the hospital from Bromsgrove and also back and forth to South Wales. Approximately a week later we had the awful phone call regarding Paul's health and we went immediately to the Queen Elizabeth Hospital in the early hours of the morning. Unfortunately Paul died.
15. As can be imagined that had a huge impact on us particularly as we all believed this was the opportunity of a way to move forward and for the health issues to be cured. We were optimistic for a healthy future.

16. We had been full of hope and felt that it would be a new beginning. That period was absolutely awful and I can recall being at my sisters house and recall other family members coming to the home in Bromsgrove when he died. It is awful to think that it all stemmed from the contaminated blood that he received.
17. We managed to arrange a funeral service before Christmas and in fact it took place on Christmas Eve. This was a lovely tribute to him and gave a little solace. We also managed to do Christmas lunch the following day and all the families were together.
18. In terms of the affect of his death, I struggled to cope with it. I didn't go into a depression episode as such but suffered normal grief reaction and also felt extremely stressed as well as upset.
19. I then recall in the New Year meeting Monica in Cowbridge for coffee and at that point she said she was going back to the United States. That news in itself hit me and seemed to bring everything back.
20. Paul had designed an extension on the back of his house. There was a lovely garden and the thought of that being sold was very upsetting and it was the last tie with Paul almost. However we still travel around South Wales to see the buildings which Paul designed.
21. Monica moved to the United States but fortunately we have maintained a good relationship with her and with our granddaughter Tia. However the loss of Paul has left a great vacuum in our lives and we miss him greatly.

## **6. Treatment/Care Support**

1. My son received treatment as a child at Bridgend hospital. He then attended Cardiff Royal Infirmary and later he attended the Haemophilia Centre at UHW.
2. My son received Hep C treatment at Queen Elizabeth hospital in Birmingham.

**7. Financial assistance**

1. I would confirm that I am not aware of having been offered any counselling support in relation to matters or financial assistance.
2. I am not able to provide any information to the Inquiry as to what assistance may have been received by Monica although I believe she did receive some payments.

**8. Other Issues**

1. I would confirm that my husband and I are still part of Haemophilia Wales. We were involved with the Archer report and also attended Parliament to hear David Owens speak. We felt confident at that time help would be given to all families.
2. We have also been involved in meeting Julie Morgan and Jane Hutt both when Julie Morgan was MP and then later as an Assembly Member. Both have been very supportive, sympathetic and helpful.
3. As indicated I remain a member of Haemophilia Wales and I am particularly committed to an ongoing action to try to obtain answers.

**Statement of Truth**

I believe the facts stated and this witness statement are true.

Signed... GRO-C

Dated... 24.1.19.