

Witness Name: Bethan Summers

Statement No: WITN2561001

Dated: 7th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BETHAN 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 Bethan Summers will say as follows: -

1. Introduction

1. My name is Bethan Summers. My date of birth is GRO-C 1967 and my address is known to the Inquiry.
2. I confirm that I am the sister of Paul Summers. My Brother sadly passed away from complications relating to Hepatitis C as a result of receiving contaminated blood products. I am in fulltime employment with Great Western Railway as part of their recruitment team.
3. I confirm I was affected by the infection of my Brother with HIV and Hepatitis C ('Hep C'). Unfortunately, despite receiving a liver transplant, Paul died on the 16th December 2008.

2. How Affected

1. I confirm that Paul suffered with haemophilia. As a child, I knew that Paul had haemophilia. I can recall Paul would have several visits to hospital and I recall him also being hospitalised for a period of time. I can recall visiting him in hospital. Paul was a fussy eater and I remember myself, my Mum and Dad smuggling in fish and chips for him to try to perk him up.
2. I do not recall the durations of those stays precisely. The stays would have been for him to have a treatment with replacement blood products for his haemophilia and I assume it would have been Factor 8 that he received at that point in time.
3. I also recall that when Paul was about 14 or 15 years of age he began treating himself at home. I can recall the Factor 8 replacement blood product being stored in the fridge and I recall that Paul had the ability to self-treat. I can also recall watching him medicate himself sometimes and it became fairly a routine although ad hoc process and part of our family life.
4. Paul went away to study at University at Bristol for a short time. He left that course and then went onto Plymouth to study Architecture. I obviously did not have a great knowledge of Paul's treatment nor precisely how he came to be infected with HIV.
5. Paul's wife Monica and my Father would have far more information in terms of the exact medical details regarding to Paul. Certainly, they would have a precise recollection of when Paul became infected with Hepatitis C. I do however recall my Mother and Father sitting me down and telling me that Paul was infected with HIV.
6. That was obviously something I never expected to hear and even now, all these years later it still causes real upset. I know this would have been when Paul was in Plymouth. In terms of the way in which it was dealt with then of

course, it was a very sensitive personal family situation. The publicity in terms of HIV was just beginning to increase and there was definitely a bit of stigma attached to it. I recall that the perception at that time was that it was an infection spread by homosexual sex and infected needles.

7. There was no real understanding of it and therefore it was very much a stigma. I felt no stigma attached to Paul but I believe that was the wide perception amongst the general public. Paul himself was a very private person and as a family, we very much kept it to ourselves. We did not talk about it to anyone outside of our very close family group. We basically resolved to deal with it as a family and to do what was needed to give Paul the best quality of life possible.
8. I recall that we also treated it on a need to know basis so that if people outside of the family needed to know then they would be told about it but otherwise they were not given any information.
9. I confirm that the impact personally upon me was a very upsetting one. At the time, I was doing my GCSEs and was then looking to go out to work. I trained as a medical secretary and worked at the Dental Hospital in Cardiff. I was therefore able to visit Paul if he was in hospital and also pick up any medication that he might require at home. I recall wanting to do as much as I possibly could to help him.
10. I recall us going to visit Paul on many occasions in Plymouth and we would stay at the Holiday Inn on Plymouth Hoe. Paul had many friends in Plymouth but when we visited the four of us would go out together. After the first year of college, I can recall Paul being picked up by dad to go home at the end of term. I remember him saying he needed to nip off and do something and it transpired later that he had in fact been off to see Monica before she left and went travelling.
11. I can recall receiving postcards from Monica to Paul and information came out about Paul being in a relationship with her. The following year when Paul went

back for the second year, he lived with some friends in a rented house. I remember him going to the United States as part of his course and I know he went to see Monica after that and their relationship blossomed from there.

12. I don't recall Monica coming over until they were actually engaged but I can remember Mum speaking to Paul on the phone when he told her that he was with Monica and they were going to get married. I can recall her saying "you cant" thinking Paul, meant he was going to get married immediately.

13. The wedding was planned, Monica and Paul married, and they lived a good life with Paul largely being in good health. I have a memory of those being good years and I recall Paul staying with me in the hotel the night before his wedding. I can recall him sitting on the balcony going through his wedding speech and that is a very fond sibling memory that I have of Paul.

14. After they married Paul and Monica moved around quite a bit from Bristol to London then eventually moving back to Cardiff. Monica lived in the Vale of Glamorgan whilst Paul worked in London. I recall Paul working very hard but carrying on very much as normal. I believe at that point he started to take some medication although I cannot actually remember what. I also believe it was about that time that he would have become infected with Hep C although again I cannot be certain as to dates and what the background to that was.

15. I would confirm Paul was a very driven and positive individual and therefore he very much had a can do attitude of continuing to work and to cope with the health issues that he had.

16. He loved work and he won a number of awards for his work in architecture. Paul was very modest and occasionally it would come out in conversation that he had received an award. Whilst Paul was obviously very proud, he never boasted about things like that.

17. I became aware that Paul was going back to London for medical appointments and I recall that he had a heart problem suffering from severe hypertension. I confirm obviously Monica knew far more than I did about what was going on and the information that we received tended to come from Monica.
18. I can recall that a test then identified a problem with his liver and identified that he had grown a tumour on his liver. As a result, he was being considered for a transplant. This would have been approximately 2006/2007. I can remember those dates reasonably well as at that point I was living in London between 2005 – 2007.
19. Paul had to go back and forth to Birmingham to the Queen Elizabeth Hospital to complete tests and to be considered for a transplant. I can recall feeling very scared for him and there was a fear of the unknown in terms of the transplant. It was a case of waiting in the hope of a match.
20. One of the big impacts upon Paul and Monica was that they were not able to have children of their own and therefore they adopted a daughter Tia May by this stage. She was 14 months old when she was adopted and was a distraction for all of us. We all tried to continue carrying on as normally as possible and I recall two separate calls in October and November when there was a prospective donor and Paul raced up to Queen Elizabeth Hospital in Birmingham only to find that it was in fact not a match.
21. I also recall that I started my current job and obviously had to confide in my line manager in case I needed to go to Birmingham. Fortunately my employers were understanding and simply told me I should do whatever I needed to do. The whole issue in terms of the failure of the match up was very stressful and upsetting for us and it was very difficult for me personally to appreciate or imagine what Paul must have been going through.
22. On 8th December 2008, I can recall another phone call being received. Paul again went to the Queen Elizabeth Hospital together with Monica, my parents,

myself and Tia-May. This time there was a match, and an operation was undertaken on the 9th December.

23. I can recall there was family accommodation at the hospital and Monica managed to stay there. Tia was with myself and my parents and we were staying at my aunt's house in Bromsgrove. It meant that Monica could focus on spending her time with Paul. I remember the hope was that the operation would be a success and that Paul would have a new lease of life. We knew from information provided that the transplant meant that Paul would no longer be a haemophiliac and his quality of life should improve.

24. The operation was carried out and we were initially told it was successful, however the hypertension became a concern as they realised how bad the hypertension was. I know from information passed to us that when the Anaesthetist realised that there was an issue there was a very difficult choice as to whether they should go ahead with the operation or abandon the operation. With the family's consent, the operation went ahead and the transplant as indicated was successful but Paul was placed on a ventilator. He was very ill but there was hope that he would pull through and be OK.

25. I can recall being at my aunts house when a senior nurse telephoned about 4am – 5am in the morning to say that Paul was very ill and should get to the hospital. I drove there and my parents were at home in South Wales and were driven up by one of Paul's work colleagues.

26. Fortunately, we all managed to get to the hospital in time to spend the last moments with Paul and we were all absolutely devastated by his death. I can only describe it as a piece of jigsaw taken away that can never be replaced. I had and still have, a huge sense of loss and emptiness and a void that can never been filled.

27. I still find it hugely difficult 10 years later and the grief and the emptiness just do not go away. It is really a case of attempting to live with it. I would also confirm there is anger at the fact that Paul was infected through absolutely no

fault of his own and through products supplied by the NHS. The Health Service is something that we put our complete and utter trust and faith in and yet this is what happened. More recently, I think there has been a realisation amongst all of the family that we could have and perhaps should have challenged the medics more.

28. I know that dad in particular has had that feeling as he had the upmost faith in Professor Bloom and there was no cause to really question what he was doing. I did not have any direct dealings with Professor Bloom myself, although I recall going to appointments at the Haemophilia Centre at the University Hospital of Wales. However I cannot remember the precise details of why and when.

29. Unfortunately after Paul's death Monica and Tia went back to the States and fortunately we have all managed to maintain a very good relationship with them albeit long distance. Over the last 5 – 6 years that relationship and in particular my relationship with Monica has been as good as it ever has been and she is hugely supportive of my parents. I still regard her as my sister-in-law and she refers to us as her in-laws, which is very comforting. I have been out to the States to see them and it has been very good for me and indeed for Tia. When I see Tia, she talks of Paul and how much she misses her Daddy. Monica herself of course has been hugely affected.

3. Other infections

1. I recall that Paul started suffering from severe hypertension.
2. My brother developed a growth on his liver and as a result he was being considered for a transplant. This would have been approximately 2006/2007. I can remember those dates reasonably well as at that point I was living in London between 2005 – 2007.

4. Consent

1. I would confirm that I am not in a position to provide any further information in relation to that.

5. Impact

1. The impact personally upon me was a very upsetting one. All I wanted to do was make my brother as comfortable as possible.
2. There wasn't day that went by when my brother was unwell that I didn't think of him. We did not talk about it to anyone outside of our very close family group. We basically resolved to deal with it as a family and to do what was needed to give Paul the best quality of life possible.

6. Treatment/Care Support

1. I confirm that Paul had no real difficulties in getting treatment or support that I am aware of but I do not know whether he was formally offered any counselling. I would confirm that I have not been offered any kind of counselling or support.

7. Financial assistance

1. I believe that there may have been some assistance but I do not know the details of that.

8. Other Issues

1. None.

Statement of Truth

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

Signed.....

GRO-C

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Dated.....*7 April 2019*.....