

Witness Name: Naomi Shelton

Statement No: WITN1034001

Exhibits: 0

Dated: January 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NAOMI SHELTON

I, Naomi Shelton, will say as follows:-

Section 1. Introduction

1. My name is Naomi Shelton. I was born on GRO-C 1982 and I live at GRO-C
GRO-C, Nottinghamshire GRO-C
2. My father, Allen Jon White (born on GRO-C 1953), was infected with the Human Immunodeficiency Virus (HIV) through contaminated Factor VIII (FVIII) concentrate. He died on 7th November 1991, aged 38.
3. This witness statement has been prepared without the benefit of access to my father's medical records. I believe that they were all destroyed.
4. My mother, Christine White-Cannon has provided her own Statement to the Inquiry (Witness Number WITN1035)

Section 2. How Affected

5. My father (Dad) had severe Haemophilia A. He was treated at the Bradford Haemophilia Centre at the Bradford Royal Infirmary (BRI) under the care of Dr Liakat Parapia.
6. Dad was told that he was infected with HIV in 1987, through a batch of FVIII concentrate given to him during my mother's pregnancy with me in 1981/1982.

Section 3. Other Infections

7. I am not aware of any other infections.

Section 4. Consent

8. As there is no proof of it, I am unable to comment as to whether Dad was ever treated or tested without his knowledge, consent, full information or for the purpose of research.

Section 5. Impact of the Infection

9. I refer to my mother's Statement as an overview of the impact of the infection on Dad and our family.
10. I was just 9 years old when my Dad passed away. I don't remember all that much. I don't remember specifically being told that Dad had HIV, but I spent my childhood knowing that my Dad was going to die. I just always knew that one day, he would be gone.

11. Dad tried to make the best of all situations and he bought a video camera so that we would have videos to look back on and so that we would have something for the times when we couldn't remember. There are so many things that I don't remember because I was so young, but I have been able to watch the videos back and I am so thankful that we have that privilege. It does however mean that there are lots of things that I don't know if are from my memory, from a video I have seen or whether I have been told that something specific happened.
12. I do remember some horrible times – like going to London for a Haemophilia Society excursion and looking forward to getting on the boat along the Thames, but having to get out of the waiting line and then we missed the boat because Dad was coughing up blood on the pavement. I remember the times when Dad was so weak that he had to be in a wheelchair as he couldn't walk very far. I could see the pain and effort it took him just to walk small distances, and even going up the stairs to bed would make him breathless. My Mum and Sister did all they could to hide things like that from me because I was so young, but there were some things that they weren't able to shield me from.
13. Before Dad got poorly and weak, we would go places at the weekends and had as many holidays as we could. We knew that we only had limited time and so we were trying to make as many memories as we could. We would go to town every so often and do some shopping and get some lunch together. I don't really remember the early times with Dad there, as once he got too poorly to come, we would go just the three of us and we would take Dad some lunch home in a takeaway box and sit in bed with him when we got home so that he didn't miss out on the whole thing.
14. Dad was very brave and he went to talk to school children and 6th formers about his HIV so that they would stay away from things that could get them infected

Although his infection was through no fault of his own, he wanted to use it for good and try to help anyone else from getting the awful infection.

15. Dad fought and fought for justice and went to court cases and hearings etc to tell his story. He spoke to newspapers, TV news and radio to get his story out there. It really should not have taken this long. Although this is a painful experience to re-live the past and all the negative, I'm doing it for him, to make him proud, to try to fight for the justice that he deserved and that he wanted for all of the people who have been infected and affected.

16. Our parents were very upfront with us. They wanted us to be fully informed about it all in the hope that we would be able to deal with any questions and comments directed at us. We hoped that with it all being common knowledge then there would be more discussion. Because of that, I had very few unpleasant incidents through the stigma associated with HIV/AIDS. On one occasion, a boy said he didn't want to sit next to me in the dinner hall and the school sent him home and informed his parents and he never said anything again. I think he had overheard something in his own household repeated by him without fully understanding what he had said - like maybe my dad was a 'druggy' or 'gay'.

17. I was scared if Dad ever got poorly in case it was the thing that finally killed him. When we were sick, we tried to keep our distance from him. If we had a sniffle or a cold, we were frightened he would catch it and it might be what tipped him over and killed him. As a child it was a lot to worry about. We spent a lot of time with my grandmother. She was like a third parent. She looked after us when mum was busy looking after dad, or if dad was too tired to drive us to school, or cook. We were very lucky that we had her so close so she could stop by at a moment's notice.

18. Dad was always a happy and jokey person, but as he started to deteriorate, he was less himself and became confused more easily. It was hard to watch him ask simple questions he should have readily known the answer to. I went with the flow and it is only now, looking back, that I realise how odd his behaviour was getting. He became paranoid. My Mum and sister tried to shield me from the worst of all of it.
19. I had an awful time after he died and as a teenager – I struggled with depression, anxiety and substance abuse for years and have needed medication and counselling.
20. I was bright at school. I would have liked to have become a physiotherapist like my Mum and needed good grades. When Dad died, I stopped enjoying school and went off the rails. Mum found me a tutor (he later became my stepfather) and I obtained 4 GCSEs above a grade C. It wasn't enough and I was at that point less confident in my ability to be able to manage at university. I was using alcohol and drugs to cope and numb the pain. In hindsight it wasn't helpful at all. You don't fully appreciate what is happening to you at the time.
21. The impact of what happened to my Dad became more apparent further down the line and the impact is huge. I married at the age of 21 and, notwithstanding the fact that I grew up wanting to one day have children, we decided against ever becoming parents. I could not contemplate the risk of passing on the haemophilia gene and for a child or grandchild of mine to ever go through what my Dad had to endure. I suffer with PTSD. The trauma of what happened to my Dad during my childhood is a contributing factor.
22. When I found myself pregnant with my daughter (my little 2½ years old miracle) my fears were renewed, and her birth was a traumatic one. I had a massive bleed and nearly died in theatre. Because of what happened to my Dad, my trust in the medical profession has been profoundly impacted. I woke up in intensive care to learn that I had been given a blood transfusion and I was

horrified and frightened. I immediately thought 'What if I've been infected? Is the blood really safe?' Having PTSD leads you always to jump to the worst conclusions. My Dad trusted he had been given the best care and ended up infected.

23. The childhood I had with my Dad was filled with love and as much happiness as we could manage, but watching him deteriorate before our eyes and then having to lose him and manage without him was the hardest thing that I have ever had to live through. I will tell my daughter all about my Dad, who would have loved her so much. We feel robbed to not have him in our lives anymore. We need answers. We need justice. We need to make sure that no generation EVER has to go through anything like this ever again.

Section 6. Treatment/care/support

24. We had family counselling sessions before Dad's health deteriorated but no formal counselling and support was offered to us when Dad died. I would have taken it otherwise. My Mum later found me a residential cancer support group placement, but she only managed to do so because she knew one of the organisers. It was helpful but it wasn't tailored to my circumstances.

25. When my husband and I moved to our village 12 years ago and I registered with a new GP, a nurse taking my blood for testing immediately left the room after a flashing red warning light appeared on her computer screen. When she came back into the room, she was donned in full PPE and gloves. As I had noticed the warning on her screen, I asked her 'Do you mind telling me what that says?' and she said 'Sorry, you shouldn't have seen that. It says there is a family history of HIV'. I asked for it to be removed. We had just moved into a new small village community and I did not want us to become the target of gossip. I was very upset by the incident and to discover that we had been unknowingly and unfairly labelled as a risk to others and I felt it was a wholly inappropriate confidentiality breach.

Section 7. Financial Assistance

26. I refer to my mother's Statement.

Anonymity

27. I do not want to be anonymous and I understand that this Statement will be disclosed for publication to the Inquiry.

Statement of Truth

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

Signed.....NAOMI SHELTON.....

Dated.....14/01/2021.....