

Witness Name: Jason Jonathan Evans

Statement No: WITN1210001

Exhibits: WITN1210002-3

Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JASON JONATHAN EVANS

I, Jason Jonathan Evans will say as follows:-

Section 1. Introduction

1. My name is Jason Jonathan Evans, DOB GRO-C 1989 and I live at GRO-C
GRO-C
2. My Dad, Jonathan Evans, died in October 1993 when I was just 4 years old after being infected with HIV and Hepatitis C by Factor VIII Concentrate.
3. This statement should be read in conjunction with my Mum, GRO-B
GRO-B witness statement who can provide the Inquiry with first hand information regarding my Dad's infection and treatment.
4. I am the founder of Factor 8, the Independent Haemophilia Group.

Section 2. How infected

5. My Dad had Haemophilia A and frequently received treatment with Factor VIII Concentrate.

6. As I was very young when my Dad received treatment I don't remember much from this time.
7. His medical records state he raised concerns about the safety of Factor VIII to his doctors in late 1984, I have been told however that he was reassured that there was nothing to worry about.
8. Shortly after this he was diagnosed with HIV and he died as a result of his co-infection in October 1993 when I was just 4 years old.

Section 3. Other Infections

9. In addition to Hepatitis C and HIV, I believe my Father was also infected with Hepatitis B.

Section 4. Consent

10. I am not aware of what testing (if any) my father consented to.

Section 5. Impact of the Infection

11. My Dad's condition had a significant effect on my parent's marriage. Their relationship broke down and divorce proceedings began about a year before he died. They were arguing a lot and it wasn't easy for them to cope whilst my Dad was struggling with his infection and its associated consequences.
12. As my Dad died when I was so young, I only have a couple of memories of him. I remember playing with toys on the floors of Haemophilia centres and I know at least 2 of my birthdays were spent in Haemophilia centres.
13. The last time I saw my father and the first real memory I have of him was on my fourth birthday in GRO-C 1993. He was in bed at his parents' house and was very ill. Although I didn't understand what was going on I must have realised that this was a significant moment as I still recall it vividly.

14. I remember going to the funeral directors with my Mum and Auntie. They were both crying. The coffin was in the room with us and I remember seeing the plate with Dad's name on it. Mum wanted to see the body but couldn't with me present, so I was sent out of the room.
15. I remember the whole period being traumatic. I have a clear memory of the day of the funeral and seeing a sea of people crying. I laid a rose on the coffin and my Dad's friend, Neil Weller, recently told me that when I laid the rose on the coffin I said, 'bye bye Daddy, I'll miss you'.
16. Life after that was a bit of a mess for a while. Mum didn't cope with his death very well and I had to stay with my Auntie for about month. I took a bit of time off school and my teacher used to visit to see if I was ready to go back. I can't remember exactly how long I had off school.
17. We lived in a small village, so a lot of people knew that my father had died of AIDS, including the children at school.
18. It wasn't until I was in Year 4 or 5 that I started to get comments from other children at school about AIDS and how my Dad must have been gay. I recall one girl, GRO-D saying to me 'oh you must be the AIDS boy'. At that age, AIDS just meant 'gay' to me as this is what I had heard from other children at school.
19. It was these comments that prompted me to ask my Mum what had happened. I had never acknowledged it before because I feared finding out the answer. I thought that if I asked her she might tell me that he had taken drugs or was gay which is why I had not asked any earlier. Mum explained things to me in the simplest way she could. She told me that AIDS was a disease that had been found in Factor VIII, which was a kind of medicine that my Dad had to take. She did not mention haemophilia at that stage.

20. I isolated myself as a child. I spent a lot of time on my own and felt very different from other children. Not only did I have to deal with the death of my father, but also the way in which he died. I had friends whose parents had divorced but no one who was in a similar situation to me. At times I doubted the story my Mother had told me and thought perhaps she had made it up to protect me.

21. The internet became more accessible just before I started secondary school. The first search engines were available, so I started to research Factor VIII and learn little bits about it that way. As search engines were still in their infancy, I was unable to get much information. I also inundated my Mum with questions about my Dad throughout my teens, but I had to stop asking her about him and his infection when I realised how upsetting she found it. When I asked questions it often reduced her to tears.

22. This was the beginning of my need to find out as much as I could about what happened to my Dad and that research has continued to the present day.

23. My paternal grandparents didn't maintain much contact with my Mum GRO-D

GRO-D

24. GRO-D to contest my Father's Will shortly after he died as he had left everything, including the house to me, but I was only four years old so his will was not honoured. I find it very distressing to this day that his final wishes were not carried out and that I lost our home.

25. I didn't see my paternal grandparents again until I was around 15. They still lived locally, and I just knocked on their door one day. My Grandma cried when she opened the door and said she knew I would come back one day. Unfortunately, she developed dementia 2-3 years after this and died around 2009. During the latter stages of her dementia she called me by my father's name which was tough.

26. When Dad died his ashes were scattered in a rose bed in his parent's garden. My Grandfather passed away in 2013 and the house has new owners, so I now have no grave or anywhere to go to remember my father. I find this very difficult.
27. I had a good relationship with my maternal Grandfather. He was the male role model in my life when Dad died. Without him things could have been very different. He introduced me to electronics and electronic encyclopaedias and I recall at one time I even tried searching for Factor VIII on these. I obviously still missed my Dad and his death left a gaping hole in my life, but I was lucky enough to have a good male role model as I was growing up.
28. Despite that I still made a lot of bad decisions in my teenage years. I felt isolated and got in with the wrong crowd. Because of what the system had done to my Dad I fought against it in every sense – I fought the education system and the law. It was my way of saying “screw the system”. I bunked off school a lot and didn't even turn up to several of my GCSE exams. I felt that the system owed me something that I would never get back. I made a lot of bad decisions because I felt the system had killed my Dad.
29. When I was 18 my grandfather gave me a pack of paperwork left by my dad. This contained court documentation from the HIV litigation and his medical records. Within these documents was a draft witness statement that my Mum and Dad had prepared at the time of the HIV litigation in 1991 and a letter from my Aunt written in support which I exhibit at **“WITN1210002”** and **“WITN1210003”** respectively. Reading these gave me a much greater insight into what had happened and what life had been like for my parents at that time.
30. When I first read my father's records from the Oxford Haemophilia centre I was struck by the notes made by the doctors which read like a diary; a chronology of his life. This provided me with some answers as to the timings of events.

31. As I continued to find out more information, I got increasingly involved in campaigning. However, having to go through all this information was emotionally very difficult for me. I particularly struggled between 2015 and 2017 and during that period I was drinking often.
32. I have had anxiety and panic attacks since my early teens. I have suffered from globus hystericus (the permanent sensation of a lump in my throat) since I was around twenty-one which my doctor says is due to stress and anxiety. It is a horrible sensation which makes me feel like I am being mildly strangled, this is constant and twenty-four hours a day. When I was younger the doctors told me I just needed to relax and read a book to alleviate this. More recently, one doctor asked me if I wanted to have a camera stuck down my throat despite the fact it is clearly a psychiatric issue.
33. I find it very difficult to have empathy or sympathy for others. I can be quite emotionally cold, and I have a lot of barriers up. I think this has and does hinder some of my relationships with people.
34. The stigma surrounding Dad's infection was definitely at its worst when I was in school. I recall confiding in one high school girlfriend about how my father died. Her response was to immediately ask me if I had AIDS too. I have had this reaction several times when talking about my father and it makes me very reluctant to discuss it with people. Since then I have tried adopting an attitude of not caring about what people think.
35. My father's death and the stigma I faced at school definitely impacted upon my education and school life as set out at Paragraph 26 above.
36. I finally decided to get my act together and go to college to study music production. However, because I had to pay fees I dropped out shortly after because I wasn't working and could not afford it.

37. My GCSE results were poor, and it has been tough for me seeing my friends follow the more traditional path of a gap year followed by university. I feel that I have missed out on this experience because I struggled in my teenage years because of my Dad's death. I was consumed by the past as opposed to focused on the future.
38. I was working full time until 2016 when my campaign work with Factor 8 increased. I approached the company I was working for at the time and explained that I intended to work for myself and would take them on as a client to continue doing some work for them if they were agreeable to that. They agreed, and I therefore reduced my workload by close to 50% so that I could spend the other amount of my time doing unpaid work with Factor 8. I am therefore only doing paid work around half of the time which has had a significant impact on my income.
39. Running Factor 8, campaigning for the truth and all of the work that goes along with that is almost like a full-time job in itself; it is extremely time-consuming.
40. When the Inquiry is over, I would like to return to full time paid work. I would also like to continue doing some voluntary advocacy work for people currently receiving treatment for haemophilia and in need of help.
41. It is only through campaigning that I discovered that my Dad had been adopted at birth and was put in touch with his biological sister. She told me how her other brother (my Dad's biological brother) was also a haemophiliac and was co-infected with HIV and Hepatitis C because of receiving infected Factor VIII. He died a couple of years after my Dad, so I never got the opportunity to meet him. This was just another reminder of the extent of the devastation caused by the contaminated blood scandal.

Section 6. Treatment/care/support

42. I was never offered counselling when I was a child or teenager. Looking back now it seems strange that this was not made available to me as a young boy who had just lost his father.

43. When I was older and going through a difficult time (between 2015 and 2017) I called the MacFarlane Trust to enquire about counselling. They told me to contact the Hepatitis C Trust who informed me they had run out of money years ago for counselling.

44. I then wrote to the MacFarlane Trust and told them it might save my life if they provided counselling. I was feeling overwhelmed and consumed by it all at the time. It was only then that funding was made available to me. I was given a set grant for funding and had to make the arrangements with the counsellor myself. I managed to find a counsellor in Coventry with experience in childhood bereavement that I saw for about 8 sessions.

Section 7. Financial Assistance

45. As a child of a deceased parent, I was made to feel that financial and other assistance wasn't there for me; it was only for those infected and their widows.

Section 8. Other Issues

46. I am the founder of the Factor 8 support group. I have organised numerous community events and protests. I have spent hundreds, if not thousands of hours reorganising the campaign, analysing and reviewing documents and doing research over the last few years. I have attended countless meetings with politicians, lawyers and others. I have sent hundreds of Freedom of Information requests and hundreds of letters to the pharmaceutical

companies, Department of Health, politicians, lawyers and the Government in my quest to uncover what happened to my Dad.

47. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my Solicitors preparation of this statement does not cover investigative work. I would like to give evidence on the matters set out at Paragraph 47 above and I am unable to do so in this statement.

Anonymity, Disclosure and Redaction

48. I confirm that I do not wish to apply for anonymity and I understand that this statement will be published and disclosed as part of the Inquiry.

49. I would like to be called to give oral evidence at the Inquiry in relation to my investigatory work and other work in my capacity as Founder of Factor 8. I do not wish to give detailed oral evidence about my personal circumstances and family history.

Statement of Truth

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

Signed..... GRO-C

Dated..... 30/11/2018