

Witness Name: SEAN BRIERLEY

Statement No: WITN1104001

Exhibits: 0

Dated: DECEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SEAN BRIERLEY

I, Sean Brierley, will say as follows:-

Section 1. Introduction

1. My name is Sean Brierley. My date of birth is 1966 and I live at East Sussex .
2. My father, Brian Brierley, was infected with Human Immunodeficiency Virus (HIV) from contaminated blood. He died from pneumonia on 1991 aged 49.
3. This witness statement has been prepared without the benefit of access to my father's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. My father was born in 1941 in , Lancashire. He was one of two brothers diagnosed with Haemophilia B (otherwise known as Christmas disease). My father and his older brother, Alan, were born to working class

parents. My grandmother was a millworker (at the cotton mills) and my grandfather worked at Platts as a semi-skilled engineer. He was serving in the Royal Marines when my father was born. My father and his brother were active boys who both played rugby and were very good at it. They spent a lot of their childhood in hospital (the Oldham Royal Infirmary, I believe) being treated for bleeds and ultimately had to stop playing rugby. I understand that they had been given snake venom from Australia when they had tooth extractions and were given cryoprecipitate when they had bad bleeds. My grandparents wanted their sons to study hard and make something of themselves because of their unsuitability to manual labour. They both studied hard and went on to become pharmacists.

5. My dad was a student when I was born. He studied at Sunderland College. In or around 1969, after my father had completed his studies, we moved to Liverpool and my father was treated there under the care of the Royal Liverpool Infirmary Haemophilia Centre. My younger brother Stephen was born in 1970.
6. My father was first treated with Factor IX (FIX) some time in the mid to late 1970s. I remember he would inject himself at home. He did not hide his treatment from us. He would talk to Stephen and me about it. He would make a game of it, inviting us to pull the tourniquet whilst he administered the injection. FIX provided him with freedom he had not previously enjoyed. We were at that time able to start taking family holidays abroad. I remember my father explaining to airport officials and hoteliers what the FIX was for and how it needed storing (in the fridge).
7. My father would still need treatment in hospital at times. I remember visiting him there as a child. While he was quite open about his treatment, he was at times in a lot of pain which he would bear without complaint. I saw him with massive bruises on his body and all over his back. As a pharmacist he was adept at managing his own treatment. He would see the minor bleeds through without treatment, just pain relief and would treat major bleeds with

FIX. There was a lot of pain management. At times he struggled to walk because of bleeds into his joints but tried to hide that from us.

8. My father's pharmacy was located in a crumbling Victorian building in Kensington, Liverpool 7, a deprived area of the city. He was well respected in the community and had a deep social conscience. He supported and agitated for many left-wing causes in, supporting the unions, social housing, CND, anti-apartheid and always stood with those seeking justice. He was a political activist and a staunch supporter of the NHS and its values.
9. No advice was given to my father before being treated with FIX about the risk of infection. In fact, he was specifically assured that it was safe to take. My father questioned/challenged the nurse providing his FIX in early 1985. He had been reading in the Royal Pharmaceutical Journal and other medical publications about contamination, as well as reading advice from the Haemophilia Society. My father was told by the nurse, under instruction from the haematologist (I do not recall his name), that Factor IX unlike Factor VIII was from the UK, not the USA, and had been heat-treated and was, therefore, safe to inject without fear of infection.
10. My father confided in my mother that he did not trust the haematologist or the Haemophilia Society because of other things he had been reading. He also felt in himself that his health was not as it should be. He went back to the Liverpool Royal Infirmary requesting an HIV test. He had the test and received a letter in the post in the Summer of 1985 telling him he was HIV positive.
11. I was at University and my brother was about to attend University at that time. My father and mother did not tell us that my father had HIV before he died. They wanted us to be protected from that information and to be left to pursue our studies and subsequent careers without disruption. Before his death my father was a party to the HIV litigation that ended in 1991. The solicitor with conduct of that litigation, Graham Ross, has since told me just how angry and betrayed my father felt to be lied to by the nurse who informed him that FIX

was safe to use. My mother has told me the same thing. Unfortunately, the files from the 1991 litigation have now apparently been destroyed.

12. My father was told of his HIV diagnosis by letter which was clearly very wrong as a means of communicating such devastating news.

Section 3. Other Infections

13. I do not believe my father to have received any infection other than HIV.

Section 4. Consent

14. I have no reason to believe that my father was treated or tested without his knowledge and consent.

15. My mother was tested after my father's death and thankfully she received a negative test result. I went with her to collect the result. My parents knew that HIV could be transmitted through sexual intercourse so it changed their life in that respect.

16. After his death, I was informed that my father had been given AZT and that he was an early trialist. My understanding was that this was part of a controlled test.

Section 5. Impact of the Infection

17. At the time of my father's HIV diagnosis, HIV was considered to be a death sentence. It was a secret between my parents. My grandfather had died in the early 1980s and my Uncle Alan died in 1986 after a failed kidney transplant at St Mary's Hospital in Manchester. My father did not tell my grandmother about his HIV diagnosis. She was a haemophilia carrier. She was the family matriarch with Irish roots. She was a strong woman but the loss of one son and the knowledge of my father's diagnosis in addition to her

own feelings of guilt at being a carrier would have been too much for her to bear.

18. The stigma of HIV/AIDS at that time was unimaginable. For it to become known that the local pharmacist had HIV or AIDS would have put them at risk of physical harm and destroyed the business. The business would have been adversely affected and everything that my father had spent a lifetime building would have been destroyed. You heard stories of people suffering with HIV having paint daubed on the walls of their home with 'AIDS scum'. They were fearful of the impact the resulting stigma would have had on Stephen and me.

19. My father was a big man and he lost a lot of weight in the last few years of his life. He became unwell in the Winter of 1990 and was admitted to hospital with pneumonia in January 1991. Steven was studying in France and I was completing a three year apprenticeship in journalism in London. We were called back home and we visited my father in hospital. He was very ill, on a nebulizer. He had very many visitors (some of whom have confided in me recently that they suspected he had AIDS) and well wishers. He was very popular. He seemed to be making a bit of a recovery, to the extent that I returned to London to go back to work. His heart failed and he died GRO-C. GRO-C My father's friend phoned me and told me. I returned home immediately and it was only then that I learned for the first time that he had AIDS. The news was devastating.

20. As a journalist I have an inquisitive mind and I had been concerned about his weight loss. I had actually asked him outright if he had HIV and he assured me he had not and that it was 'just hepatitis'. Towards the end he had lost so much weight he was barely recognizable. In retrospect, it was obvious but back then I wanted to believe him (although I now know that hepatitis C can be equally as deadly) and I was relieved.

21. I was angry when I found out my parents had not told me (although I now understand and I respect their feelings). I argued with the Registrar when registering my father's death as I did not want AIDS of his death certificate. I

wanted the cause of my father's death to be recorded as a heart attack. I talked to my father's haematologist about my father's death and involvement as a guinea pig in the drug trial. I also later visited Graham Ross to learn more about my father's participation in the class action. The decision to agree to the settlement had been a very hard decision for my father to make. My mother said that they attended the litigation meetings. People there were dying and would likely be dead before seeing any money at all unless they all agreed to accept the money offered. The money from the class action arrived six months after my own father died.

22. My father was a great man. The crematorium at my father's funeral was packed out. You could not move there. He is lost to us and I feel a great sadness that my children never got to see and know him.

23. My father had it very tough psychologically. His brother Alan, a fellow pharmacist [GRO-C]
[GRO-C] [GRO-C]
[GRO-C] My brother Stephen had been in the Leppings Lane stand during the Hillsborough disaster and my parents waited five hours for news as to whether my brother was alive. He has had survivor's guilt and has found it hard to cope with what he witnessed there and with the trauma of what happened to our father. He cannot talk about any of it.

24. My mother found it hard to cope with my father's death and the circumstances surrounding it. She finds it hard to talk about it to this day. She now hopes that we are going to get justice, so she has started opening up to me. She says that the loss of my father is like someone having taken the ground from underneath her.

25. My father's pharmacy was sold soon after his death. I had to leave my job and return to Liverpool to support my mother. We struggled to keep the pharmacy going with locums and lost money. We sold the business for a knock down

price. I took a lesser paid job at John Moore's University as a lecturer. I did that for three years, before returning to my journalism career in 1994.

Section 6. Treatment/care/support

26. A Counsellor was made available to my mother after my father's death when she took her HIV test. I do not believe my father was offered any counselling.

Section 7. Financial Assistance

27. My mother received a class action payment through the MacFarlane Trust of what she believes to be £60,000. She also said that the Trust paid for my father's funeral.

Section 8. Other Issues

28. I have written a couple of pieces as a journalist expressing my dissatisfaction that no one has (yet) been held accountable in England (like other countries).

Anonymity, disclosure and redaction

29. I confirm that I do not wish to apply for anonymity and that I understand this Statement will be published and disclosed as part of the Inquiry. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed  GRO-C

Dated

2 / JAN / 2019

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This Medical Summary has been prepared without the benefit of access to my father's medical records.