

Witness Name: L M Paintin
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Exhibits: 0
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LOUISA MICHELLE PAINTIN

I, Louisa Michelle Paintin, will say as follows:-

Section 1. Introduction

1. My name is Louisa Michelle Paintin of GRO-C
GRO-C I was born on GRO-1974. I am single. I have no children.
2. This statement is in relation to my father, Frederick George Paintin, who died on 18th January 2000 from Hepatitis C (HCV) caused by infected blood products and haemophilia.
3. This statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How Affected

4. My father had severe Haemophilia A with a 0% clotting factor from birth.
5. He received blood transfusions and fresh frozen plasma before Factor VIII was a treatment option.
6. My father was treated with Factor VIII from 1985 until his death in 2000. I recall that my father did not administer his own Factor VIII which meant that the local doctors would administer his treatment by visiting him at home. He was under the care of Dr Thorogood and Dr Williams, his general practitioners.
7. He was predominantly treated at the Churchill Hospital, Oxford but occasionally attended the John Radcliffe Hospital, Oxford. His treating consultants were Dr Rizza, Dr Matthews, Dr Trowell, Dr Giagrande and Dr Kealing.
8. Factor VIII was seen as the revolutionary treatment.
9. As far as I can recall, although I was young at the time, my father did not tell me that he had received any information with regard to the possible risk of infection as a result of receiving Factor VIII.
10. My father did not tell me when he found about his infections but I know now that he was infected with Hepatitis B in the early 1970s through a blood transfusion.
11. I also know that he was infected with HCV later in his life; the diagnosis being in the early 1990's.
12. I know that he was put on the liver transplant list but this opportunity was taken away from him and I feel he was left to die.

Section 3. Other Infections.

13. I know from some of his medical records that he was exposed to the risk of vCJD and he received a very matter of fact letter in relation to this.

Section 4. Consent.

14. I know that my father was tested for HIV several times. He was HIV antibody negative. He never told us about these tests and I can only believe that they were conducted without his knowledge and therefore impliedly without his consent.

15. I strongly believe that my father did not know that he was being tested.

16. I strongly believe, although I cannot prove, that my father was used as guinea pig. I understand that he was one of the first haemophiliacs in the United Kingdom to have his appendix taken out and to be given a blood transfusion on the operating table by a live blood donor. He was approximately 9 years old at the time. I believe the research continued throughout his life.

Section 5. Impact

17. My mother is Barbara Jean Paintin and she has provided a statement to the Inquiry which I have seen. I agree with what my mother says in terms of his characteristics. He was a very private man who was very protective of his family. He did not want to worry us at all.

18. Mentally, he was an extremely strong character. Not in a "*macho-way*". He never complained and he was wonderful. He always said that "*life was for living*". He was determined. He was a very smart man. He hated fuss and emotion, just like I do. He used to worry about his family and not about himself very much.

19. Physically he remained asymptomatic with HCV until the late 1990s. He then had long periods of jaundice.
20. In 1998 he was put onto a liver transplant list but was taken off the list in 1999 as the doctors said that his condition had improved. However, after he had been taken off the list his condition appeared to deteriorate and over Christmas 1999 he became very poorly.
21. I remember saying to his GP, Dr Thorogood, two nights before he died that I had found a place in America that would treat my Dad and I asked why they would not treat him in the UK. Dr Thorogood replied that it was a financial issue, his treatment would be too expensive. I think he should have been monitored a lot more closely since the date he was diagnosed and he should have been scanned and given liver function tests more regularly.
22. When I was approximately 11 years old, I was nosy and I would read letters in the house addressed to my father from the Haemophilia Society which mentioned HIV. When the gravestone adverts came on the TV with regard to AIDS, I started questioning everything internally. I did not voice anything with my parents. I always knew that something was wrong with my father, but I did not know exactly what was happening to him.
23. In 1989 when I was 15, I started dating. His parents did not want him coming to our house. This boyfriend and other people at school would ask me whether I had AIDS or whether my father was infected. It was at that time in the media there was a connection between haemophiliacs and AIDS.
24. At this point in my life, I tried to commit suicide for the first time. I took a lot of pills and ended up in Warwick Hospital. The doctors there told me not to be so stupid and this was their way of counselling and their way of mental support.
25. My Dad used to joke "I'm about the only haemophiliac in the Country without HIV" when the stories hit the papers that haemophiliacs were linked to AIDS.

26. It was in 1996 when I was staying with my mum's cousin's husband "Swanney" that I was told my dad would not be around for much longer and that I would have to toughen up. At this time, I was a teacher as part of my University course and I was staying with him in Zimbabwe. My dad had opened up to Swanney; I think it was because he lived in another country and was detached from Dad's illness. He had spoken to Swanney by telephone and told him that he was dying. At the time I thought "of course parents die first". I did not put two and two together and did not really take this information on board. This was in 1996 just before Christmas.
27. I got on with my life and worked hard; I feel that was my way of coping with what Swanney had told me. I finished my University degree in Art and Education and went into Youth Work applying for European funding. I was very successful in what I did and I escalated through the ranks with Bradford City Council in highly paid employment. I also did voluntary work at a surgery in Bradford.
28. I had always had telephone calls from my mum saying that my father was unwell. However, on a particular occasion in 1998, it was completely different. I went to see him and as soon as I saw him, I knew he was very unwell. I began to research his illness on line and became aware of the group "Tainted Blood". I became angry with everyone and everything.
29. I started a crusade online. My anger festered; the more I read the more it escalated. This was also my way of feeling and coping with everything that was happening. I was angry at the entire world.
30. I was aged 25 when Dad died on 18th January 2000.
31. In 2000 just after my father passed away and whilst I was still living in Bradford, I went to see my GP, Dr Henderson. I was helping him design a website as a volunteer and I recall that I had a breakdown about not being able to get the correct colour ratio of the logo which I was designing on the computer. Dr Henderson, who also worked at Broadmoor Hospital said that he thought I might be bipolar.

32. He gave me a book entitled "*The Fall and Rise of Medicine*". He told me that I needed treatment. He sent me away and suggested I read up on depression. Since that time I have been on medication.
33. I think it is important to feel anger. It has triggered me to campaign. Medical practitioners have always tried to deter me from campaigning but I am now even more determined than ever to get Justice.
34. I get very cross that my father was not treated and I get cross from the medical practitioners' words that "they were doing their best". I cannot leave it alone. There is not a day that goes past that it is not in my head; it is constant. I question why I should leave it alone. For over 18 years I have been led to believe that this is an obsession and that it is a bad thing. I pay attention to everything that is going on in the media, with the groups and yes, that makes me jaded. I tell this to the psychologists all the time.
35. I came to not trust anyone. I was working at the Council and I became a "whistleblower" about misappropriation of funds within the Council. A lack of trust is constantly in my headspace and I came to the realisation that nobody cared.
36. I left the council in 2002 and secured a job managing Arts and Museums in North Yorkshire. I lasted in this job for approximately 3 years.
37. I sat at my desk at work one day, and I thought, I just can't do it anymore. This was in 2005 when I gave up completely on paid employment.
38. I had completely closed off about my father's death and I only told my doctors. I did not talk with my Mum or Aunt about the devastation I felt.
39. My condition eventually became so bad that the crisis team came to my house and attended three times a day to monitor my medication.

40. I was seeing a different psychiatrist almost every day which meant no continuation, no consistency in my mental health treatment. It was torture to have to explain everything all over again to somebody new time and time again. I could not cope.

41. In relation to my medication; I started on low doses but when this was increased I started to be violent to myself. I took overdoses but I always woke up and I was never hospitalised. When I woke up I was fed up with myself that I had woken up.

42. I did not want to die but I did not want to exist. I put newspapers up at the windows to block out the light and I didn't answer the phone. I really do wish that I had had the strength to carry on "being" and working properly. I was in a very well paid job; I now receive benefits. This is a constant worry because of the reassessments that I have to go through so often.

43. I do not trust anyone. I could not and have not had a relationship. I am a carrier of the haemophilia gene and I therefore decided that I would never have children.

44. It seems perverse but this campaign has now given me a focus.

45. I have become some sort of an anchor for people; people who are affected feel that they can talk to me.

46. I am not fulfilling my potential and this is my reason; my father's death. It should not be that way.

47. Liberties were taken away from people. People were horrendously affected. I am angry at the way we have been treated.

48. There have been insinuations of experimentation for years and years; the idea that people were used because there were not many haemophiliacs. It is a total injustice.

49. I am a realist but I do not think this should have happened.

50. In 1998 when Dad was on the transplant list we went to see the bed he would be put in after the liver transplant. We were told that someone would have to die in order for Dad to get a transplant. After this all I could envisage was someone leaving their house, not having said goodbye to their family, dying in a car accident so that dad could get a liver. I could not stop thinking about it. This was my first psychotic episode.

Section 6. Treatment/Care/Support

51. I do not believe we were given the support we required. I believe that my father should have remained on the transplant list. I wrote to a private hospital in America who confirmed that they would be willing to conduct a liver transplant at a cost. When I spoke to Dr Thorogood about this and why they would not do it in the UK he implied that it was all financial.

Section 7. Financial Assistance

52. My mother received Stage 1 and Stage 2 payments from The Skipton Fund.

53. I filled out all the applications on her behalf but my father's death certificate made the process straightforward. Dr Thorogood had insisted that "infected blood products" be put on the death certificate.

54. We would not have known that any financial assistance was available if I had not joined the Tainted Blood Group and I read online that financial assistance was available.

Section 8. Other Issues

55. In September 2017 I made an application for my fathers' medical records. I had to fill out so many forms and it became a long process. When we went to collect the records they told us to wait in the corridor and I feel the hospital treated us in a very negative way. We provided proof of address and ID as asked by the applications but they never took a copy. They handed us the notes as they said they could not send a physical copy; we were expecting more records than one lever arch folder which we received. I do not feel that we have received all Dad's notes and records.

56. I have been involved with Tainted Blood since 2007. I feel it has been a constant battle to get where we are now and I welcome the Inquiry. It occupies my mind constantly.

57. In 2002 I received a letter from Bradford Infirmary Hospital asking me to make an appointment to have tests. They told me that I was being tested for Hepatitis C which was fortunately negative. They monitored me for a while. They did not tell me whether they were testing me for HIV but they did ask me whether I planned on having children. I cannot get any of my hospital records from that period which I find is very strange.

Anonymity, disclosure and redaction

58. I do not wish to remain anonymous and understand that this statement will be published and disclosed as part of the Inquiry.

59. I do wish to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C

LOUISA MICHELLE PAINTIN

Dated *7th March 2019*