

Witness Name: DJ Metcalfe
Statement No: WITN1391001
Exhibits: WITN1391002-3
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DOROTHY JUNE METCALFE

I, Dorothy June Metcalfe, will say as follows: -

Section 1. Introduction

1. My name is Dorothy June Metcalfe of GRO-C
GRO-C I was born on GRO-C 1945. I live alone in a caravan. I am a widow and have one daughter. I tend to keep myself to myself and I very much love gardening.
2. I am one of 4 siblings (Michael Douglas Howton, Brenda Margaret Millard and Julie Elizabeth Scott), all of whom have provided witness statements.
3. I am an affected person in relation to my late father Douglas Alfred Howton and my late nephews Russell Wayne Millard and Robert Paul Millard; all of whom were infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII. Douglas died on GRO-C 1989, Russell on GRO-C GRO-C 1990 and Robert on GRO-C 2012.
4. This witness statement has been prepared without the benefit of access to Douglas', Russell's or Robert's full medical records. I confirm that

there are a large proportion of medical records which have gone "*missing*".

Section 2. How Affected

In relation to Douglas:

5. My father had severe Haemophilia A and was infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII throughout the later stages of his life. **Exhibit WITN1391002** is a copy of my father's death certificate which lists the causes of death as pneumocystic pneumonia and acquired immune deficiency syndrome and confirms that he "*contracted virus through treatment for Haemophilia*".
6. My father was never given any information or advice regarding the risks of receiving Factor VIII.
7. He received treatment at the Churchill Hospital, Oxford and his consultants were Dr Rizza and Dr Matthews.
8. I do not know when my father was infected with HIV or Hepatitis C.
9. My mother opened a letter from the Churchill Hospital which was addressed to my father and was dated in or around November/December 1985. This letter advised that my father was HIV positive. It also enclosed raffle tickets for purchase.
10. My mother did not advise my father about the contents of this letter but she did tell me and my 3 siblings and we were asked not to divulge the news to anyone; least of all my father. My mother wanted to protect my father because she knew that he would worry about such a diagnosis.
11. In any event, some months later my father also found out about his HIV diagnosis purely by chance. He attended his GP to obtain the results of a

chest x-ray which had been undertaken following a recent chest infection. The GP said to my father "*Your chest is clear but you have HIV*". The news was conveyed in a very matter of fact manner. This was a terrible way to find out such devastating news. However, I suspect that the GP thought that my father was already aware of his diagnosis. My father returned from this appointment and did not tell my mother; not realising that she already knew.

12. My father was not given any information about how to manage the infection and he was not provided with any information regarding the risks of transmission. However, my father would have carried out his own research regarding what HIV was and how it was going to now shape his life. I recall that from the moment he returned from that GP appointment, he took up residence in the back bedroom and my mother and father slept apart from that time onwards.

13. My father was also infected with Hepatitis C but he was never told that he had this infection.

In relation to Russell:

14. Russell had severe Haemophilia A and received Factor VIII from the age of approximately 18 months until his death. He received treatment at the Churchill Hospital, Oxford and his consultants were Dr Rizza and Dr Matthews.

15. Russell was infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII.

16. In or around the mid 1980's, Brenda accidentally found out about her son's HIV positive status. She was standing outside his hospital room and overheard one of the consultants, who was briefing a group of trainee doctors, say "*he should be on AZT*", whilst pointing to Russell's room.

17. Ironically, a short time after this, I believe that Russell also found out about his HIV infection by chance. He too overheard a conversation between medical professionals. Following this, Russell told Brenda that he was HIV positive, not knowing that she was already aware of this.
18. Sometime after Russell found out about his HIV, he discovered that he had Hepatitis C. Dr Rizza told Russell that he would have to be careful with his liver but rather worryingly he was not given any further information about how to manage Hepatitis C or about the risks of transmission.
19. Russell never received any information in relation to the risks of receiving Factor VIII. After he had been infected, he did not receive any adequate information in relation to how to manage his infections or regarding the risk of transmission.
20. **Exhibit WITN1391003** contains extracts from Russell's medical records which clearly demonstrate that medical staff have redacted copious amounts of information.

In relation to Robert:

21. Robert had mild Haemophilia A and received Factor VIII on an intermittent and "*as and when required*" basis. He was treated at the Churchill Hospital and his consultants were Dr Rizza and Dr Matthews.
22. Robert was told that he had HIV by Dr Rizza at the Churchill Hospital in the latter part of 1986, GRO-C Robert attended a routine appointment and did not expect to be told this devastating news but to some extent he had suspected that he may have been HIV positive because both his brother (Russell) and grandfather (Douglas) had been infected with HIV.
23. Robert was never given any information about the risks of receiving Factor VIII.

24. I do not know how Robert found out about having been infected with Hepatitis C but I do know that he was told at some point.

25. Robert was not given adequate information about how to manage his infections or regarding the risk of transmission.

Section 3. Other Infections

26. I believe that my father and my nephews were definitely put at risk of vCJD and I believe that they all developed vCJD and I set out below why I believe this.

27. In relation to my father, I distinctly remember that his coordination deteriorated towards the latter stages of his life. Sometimes he would "read" the newspaper upside down. Furthermore, my sister-in-law, Mary Howton, recalled an occasion when my father dropped a lit cigarette on his lap which burned his leg quite badly. He had not even noticed; it was like his nerve endings had died.

28. In relation to Russell, I recall that he moved like a 'rag doll'. He had no coordination and it was very upsetting to see.

29. Russell's death certificate records that he passed away due to encephalopathy and this further persuades me to think that he definitely had vCJD.

30. In relation to Robert, I remember that he walked as though he could not feel the ground under his feet. His walk was both laboured and disjointed.

Section 4. Consent

31. I strongly believe that my father and nephews were all tested and treated without their knowledge and therefore impliedly without their consent.

32. Russell had a test conducted on his "*stored blood*" after he passed away and I believe that this was a test for Hepatitis C which had clearly been undertaken without his knowledge or consent. I think he was also tested for vCJD as I believe that this has to be done.
33. During most hospital visits, Mary Fletcher who was a nurse at the Churchill Hospital would take my father's blood and I believe that his blood was used for the purposes of research.
34. Both Russell and Robert received Hepatitis B vaccines without their knowledge and therefore impliedly without their consent.

Section 5. Impact

35. I think that as children, my siblings and I lived under a cloud of Haemophilia. We were not allowed to say anything about it because my father's job would be placed at risk because Haemophilia was associated with infectious diseases. Our childhood was poor because of my father's bleeds and infections which meant that he missed a lot of work. My father had to hold down two jobs and my mother also worked in order to just try and keep a roof over all of our heads.
36. When my daughter got married in 1985, my father had put weight on for the first time in his entire life. I went out and bought him a suit and we were laughing because he had such a rotund belly. My father was horrified because, throughout his entire life, he had looked like a stick insect and that's just what he was used to. This was a happy memory of my father and I frequently look back at photographs of my father on this day. My father gave my daughter away at her marriage because her own father had died.
37. I also have a photograph of my father which was taken in 1990, and the contrast between the photographs taken 5 years apart is almost unbelievable. He had lost so much weight at this point; he looked extremely poorly and was almost unrecognisable.

38. It was not all misery though because my parents did very well to fight for us, look after us and protect us. In fact, my father was very strict with us. He wanted us to be back at home at a certain time and he used to scare our boyfriends away. My sister, Brenda, would always push father's buttons. I used to hear her strutting down the street because she always stayed out well beyond our curfew whilst I was already at home and tucked up in bed. I then used to listen to them bickering and kept thinking why couldn't Brenda just come in on time, but she never did!
39. My father was not only a loving father, but also an animal loving man. He had a dog called Bob and he worshipped that dog. My mother was always trying to get rid of the dog but my father was having none of it. He was always bringing animals home.
40. I remember one time that we were at the hospital with my father whilst he was undergoing a bronchoscopy and I recall the doctors being particularly unhelpful and not treating my father very well. I advised my father that I was going out for a cigarette but what I actually did was chase a junior doctor down the corridor to ask her how my father was doing. . She responded: *"Well, he has got the virus, so what do you expect?"*. At this stage, I had no idea it was the HIV virus. I just thought it was an everyday virus. I remember getting home and pondering on this thought and actually thought well maybe she did mean HIV but then I doubted myself.
41. As time went by, I noticed that father became increasingly poorly and he eventually stopped working altogether. I remember Brenda visiting and spending time with him and the family home. Finally, my father's legs gave up and his mobility disappeared overnight. We all knew that the loss of the use of his legs meant we had reached the stage of the beginning of the end.
42. My father was weak and lethargic. It was like the energy had been sucked out of him. He suffered with arthritis, poor mobility, emphysema and COPD. He regularly picked up various infections due to his low immune system. His liver was damaged and he mentioned that black dots appeared in his vision.

43. Mentally, he became very depressed. This was unlike his usual self and I knew that it was the effects of his infections and AZT treatment. He felt ashamed and devastated and he had nobody to talk to about his HIV because it was too dangerous to do so, in case somebody became prejudiced against our family.
44. Our mother was not the easiest person to live with back then; she was difficult. My mother and I clashed at the time. She made us stay in the same room as our father on the night he passed away. I think she knew how close he was to passing away despite the fact that she had tried so hard to look after him and keep him with us. She thought she could save him and did absolutely everything for him.
45. Our mother would have given her life in exchange for my father to be able to live. She was angry with all of us to some extent. She was even angrier with the doctors and the hospital. Before his death, my father would put on a tune and pretend that he was playing his organ. He had this positive mind set and he just wanted to make his children laugh. After he passed away, the rage in my mother was so great that one day she shoved his organ towards me and demanded that I remove it from the house. I knew that she was grieving and just trying to deal with his passing but it was so upsetting.
46. My father's passing impacted extremely negatively upon my life. I let Brenda down when my nephews were dying. I wish I had been more supportive but it just brought back too many bad memories and opened up old wounds. I remember bumping into Russell in town one day and just looking was enough for me to know that he was dying the same painful death that had befallen my father. This brought back sad memories and I could not deal with it so I distanced myself from Brenda; at a time when she needed me the most.
47. I constantly worry and I live in a permanent state of anxiousness. If there is something going on in the family or if I think someone is ill, I instantly think that the problem will lead to death. It is a horrible feeling. I have always had

this terrible fear that I won't be able to save my daughter and my grandson if something happened to them.

48. Throughout the years, I have remained silent. I do not tell anybody about how I feel, and I have kept quiet about what has happened to our family. I do isolate myself and I tend not to keep in contact with people. This means that people get upset with me because they think they are in the wrong or have somehow upset me. But I know it is just how this tragedy has affected me; I just want to be on my own. Even as a family, we always kept certain things to ourselves.

49. Since our mother passed away, we have felt like we have lost the nucleus of the family. We have all gone our separate ways, and I think it would have been better if we had remained a close knit family. However, this was not possible given that everyone was so traumatically affected.

50. Our mother's sister completely disowned our family after she found out about the infections. Furthermore, my father's sister and brothers did not come and see him when he was poorly and the next time we saw them again was at his funeral.

51. Someone once remarked to me "*I hope your mum doesn't have what your dad has got*". I think some people outside of the family must have known or at least suspected but they did not have the guts to say it outright. People did not understand, and although people are starting to, we only have friends whom we can count on one hand. Stigma has always been an issue and had ensured that our silence prevailed.

52. I remember going to see Russell, quite early on in his illnesses, in the hospital and he looked so awful. I found it so unfair because Russell did everything right; he never went out and got drunk, he dated his wife before he got married and had children and he was such a good person. He did "*everything by the book*".

53. I am grateful that Robert got the extra years that he did. His death was so sad. I do not know how Brenda manages having lost her two boys. They both left a good legacy with their children for which I am pleased.

Section 6. Treatment/Care/Support

54. I recall that my father was placed in an isolated side room following his bronchoscopy. His body went into shock and he had a seizure. It was lucky that my mother was with him when this happened because he was almost completely ignored by the medical staff.

55. I also recall my father being given a very large and extremely tough jacket potato which was covered in mud, when he was in the John Waring Ward at the Churchill Hospital. My father was so weak at this point he could hardly even pick up a fork, let alone tackle this potato which was certainly not fit for human consumption. My mother picked up the potato and handed it back to the hospital staff. This was such an upsetting sight.

56. The medical staff were always fully gloved and masked when treating my father and I also recall him being in a very cold isolation room with broken blinds in the John Waring Ward.

57. My father had his hearing tested at the Churchill Hospital and the doctor just stuck something very abruptly into his ear, without pre-warning my father. The way my father was treated was brutal and horrific. The doctors did not usually want to touch him and when they did, they made sure that it was over and done with very quickly.

58. My father was refused dental care; no private or NHS dentist was prepared to deal with him and as a result he ended up with a full set of dentures.

59. As far as I am aware, neither my father nor my nephews were offered any counselling or psychiatric support.

60. I have never been offered any counselling or psychiatric support.

Section 7. Financial Assistance

61. The Macfarlane Trust decreased my mother's widow's pension and we challenged this after she received a snotty letter from them. The process was difficult and the staff were particularly unhelpful.

62. I believe that my father received grants from the Macfarlane Trust for a washing machine, bed and mattress.

63. My mother received the Stage 1 lump sum payment of £20,000 from the Skipton Fund but this was after my father had passed away.

64. I never received a penny from any of the trusts.

65. My nephew's wives dealt with their financial affairs so I do not know which or how much financial assistance they received.

Section 8. Other Issues/Conclusion

66. We were not allowed to be involved in the 1991 litigation. I want an opportunity to fight for my deceased loved ones. I want the people who authorised the importation of contaminated blood to be held accountable for the lives lost as a result of this.

Anonymity, disclosure and redaction

67. I do not wish to apply for anonymity and 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: 12 February 2019