Witness Name: BM Millard Statement No: WITN1394001 Exhibits: WITN1394002-3 Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BRENDA MARGARET MILLARD

I, Brenda Margaret Millard, will say as follows:-

Section 1. Introduction

- My name is Brenda Margaret Millard of GRO-C My date of birth is GRO-C 1942. I am married to an American, Wayne Junior Millard, who has lived in the UK most of his life.
- 2. I have three lovely boys; my two eldest sons are Haemophiliacs and they are called Russell Wayne Millard and Robert Paul Millard. Darren Lee Millard is our youngest son and he does not have Haemophilia.
- 3. I am one of 4 siblings (Michael Douglas Howton, Julie Elizabeth Scott and Dorothy June Metcalfe), all of whom have provided witness statements.
- 4. I am an affected person in relation to my late father Douglas Alfred Howton and my late sons Russell and Robert; all of whom were infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII. Douglas died on 15th June 1989, Russell on 5th October 1990 and Robert on 14th November 2012.

1

5. 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:

- 6. 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 WITN1394002 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".
- 7. My father was never given any information or advice regarding the risks of receiving Factor VIII.
- 8. He received treatment at the Churchill Hospital, Oxford and his consultants were Dr Rizza and Dr Matthews.
- 9. I do not know when my father was infected with HIV or Hepatitis C.
- 10. 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.
- 11. 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.

- 12. 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, it was likely 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.
- 13. 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.
- 14. My father was also infected with Hepatitis C but he was never told that he had this infection.

In relation to Russell:

- 15. 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.
- 16.Russell was infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII.
- 17. In or around the mid 1980's, I accidentally found out about my son's HIV positive status. I 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.

- 18. 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 me that he was HIV positive, not knowing that I was already aware of this.
- 19. 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.
- 20.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.
- 21. Exhibit WITN1394003 contains extracts from Russell's medical records which clearly demonstrate that medical staff have redacted copious amounts of information.

In relation to Robert:

- 22. 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.
- 23. Robert was told that he had HIV by Dr Rizza at the Churchill Hospital in the latter part of 1986, **GRO-B** 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.

- 24. Robert was never given any information about the risks of receiving Factor VIII.
- 25.1 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.
- 26. Robert was not given adequate information about how to manage his infections or regarding the risk of transmission.

Section 3. Other Infections

- 27.1 believe that my father and my sons were definitely put at risk of vCJD and I believe that they all developed vCJD and I set out below why I believe this.
- 28. In relation to my father, I 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.
- 29. In relation to Russell, I vividly recall that he moved like a 'rag doll'. On the Sunday before he passed away, I telephoned my sister Julie and asked her to come and help her look after Russell whilst we waited for the ambulance to take him to hospital. By the time Julie arrived, he could not even hold himself up and it was like his muscles had gone limp. He had no coordination and it was a shocking sight and I don't think Julie has quite got over what she witnessed.
- 30.Russell's death certificate records that he passed away due to encephalopathy and this further persuades me to think that he definitely had vCJD.
- 31. 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. He

was also diagnosed with an inflammation of spinal fluids but I believe that this was vCJD.

Section 4. Consent

- 32.1 strongly believe that my father and sons were all tested and treated without their knowledge and therefore impliedly without their consent.
- 33. 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.
- 34. 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.
- 35.Both Russell and Robert received Hepatitis B vaccines without their knowledge and therefore impliedly without their consent.

Section 5. Impact

In relation to Douglas

36. My father's mental and physical symptoms were horrific following his infection with both HIV and Hepatitis C. I would describe him as "*a mess*". Towards the end of his life, my father was incredibly weak and lethargic and it was like the energy had been totally sucked out of him. My father had to be carried into ambulances. My father suffered with arthritis, poor mobility, emphysema and COPD. His liver was quite poorly and he was forever scratching his body because his whole body itched. I recall that my father commented that he could see black dots in his vision and he told me that these were described as "*liver spots*" by the opticians. He was unable to swallow despite initially having a good appetite.

- 37. Mentally my father became both introverted and depressed due to a combination of the viruses and the AZT treatment. My father really suffered because he could not open up to anyone about his HIV and he was constantly ashamed due to the stigma. He dealt with everything alone although he did of course have our family to support him.
- 38. My mother had to deal with all of my father's medication and she used to administer and control his AZT treatment. She ensured he had this at midnight and then she rose again ready for the 6am dose. My mother did a phenomenal job of looking after my father and it took its toll on both her mental and physical strength. She was on her feet all day long and she actually developed an issue with her feet whereby the bones in her feet actually collapsed.
- 39. Financially, life was a real struggle for my parents. However, they did a fantastic job of shielding us from the realities of this and gave us the best childhood they could.
- 40. Towards the latter stages of my father's life, he fully appreciated the path ahead. He came to terms with his infections because he was intelligent enough to realise that he had no choice.

In relation to Russell:

- 41. Russell passed away in 1990 aged only 27. He left behind a loving wife, Karen and two children who were Samantha, aged 3, and Daniel who was only 10 months old.
- 42. Mentally, Russell suffered in a terrible way because he was a much more sensitive and quieter boy than his brother, Robert. Russell took on board his infections and he became even more introverted and he thought deeply about the path ahead.

- 43. His depression plummeted and he was acutely aware of the AIDS epidemic which was always broadcast on the news.
- 44. He used to come to my house for the weekend and leave his wife and children at home because he was so poorly and wanted his mother to care for him. He confided in me and I tried to bolster his spirits as best I could but it was incredibly difficult watching my son waste away and mentally shrink into a shell of what he once was. I recall Russell asking me "*Am I dying, mum*?" and I said "*Of course you're not*". I was crying inside and just wanted to protect my little boy.
- 45. Russell worked for my husband and together they fitted burglar alarms. However, he quickly became increasingly fatigued which was in stark contrast to when he started out and would go up the ladders to save my husband from doing this. In or around 1990 I recall that he said "*dad please take me home*" and this was the last day he was able to work.
- 46. On one occasion, I recall that Russell and my husband attended the pub after work and some people were acting boisterously and somebody said something about AIDS. Russell turned to my husband and said very forthrightly *"I'm ready to go home now".* He did not want to get involved, argue or have anyone question why he might have a different opinion. My husband could tell that Russell felt extremely upset by the comments he had heard.

In relation to Robert:

47. Mentally and physically, Robert was the polar opposite of Russell. He was an independent and strong man. He made his own decisions and he knew he was going to take on HIV and that it was not going to beat him. He was generally reasonably healthy; or perhaps he struggled inside but did not tell me or show me the realities of his struggles. He was resilient and would not let things get the better of him.

- 48. He was on a cocktail of medication to treat his HIV and I believe that he dealt with the medication reasonably well. When Russell passed away, Robert saw the effect that it had on the family and I believe Robert kept being strong for a long time to protect us.
- 49. Robert was a man of many talents and started up a company for boarding up shops that had been broken into. He was also skilled at tiling. He tiled our neighbour's bathroom and recently our neighbour advertised their house for sale with the result that potential buyers commented about how fantastic the bathroom looked.
- 50. Approximately 18 years after Russell passed away, Robert became really ill. Towards the end of the 1990's, Robert started feeling a lot more fatigued and lethargic but he battled on and still attended work, albeit on an intermittent basis. He did become depressed as I believe that he wanted to work full time and earn a proper wage to look after his family.
- 51.As far as I am aware, Robert did not tell his friends about his HIV and Hepatitis C infections.
- 52. He used to come to our home after dropping his wife off at work and spend the mornings with us. I miss him very much.

Impact on me:

- 53. In relation to the mental impact; I do my best to cope. Sometimes I succeed, sometimes I do not. Recently, just before the Christmas of 2018, I had a mental breakdown at the doctors. I have previously been in control of myself, but I just lost it. The doctors wanted to put me on medication, but I refused.
- 54. Every morning, I wake up with a stomach churning feeling and distressing thoughts of whether I could have done something else to save them. I beat myself about what had happened over and over again.

- 55. My weight has fluctuated due to the stress and the effects of losing my father and two of my sons. I have suffered from bone marrow disease, breast cancer, arthritis, an overactive thyroid, back related problems, COPD and regular chest infections.
- 56.1 have a wonderful family who are my support network. I confided in my wonderful husband and I have never had any trouble discussing how I feel with him. I believe that this is how we kept our sanity.
- 57. When Russell passed away, the undertakers sealed his bag with a metal rod across his face. The undertakers told us that if we attempted to open the bag, they would have him cremated immediately. He was not allowed to be buried with his wedding ring and we were not allowed to kiss him goodbye. Devastation would be one word to describe what I went through but I do tend to keep my struggles to myself and only share them with my husband.
- 58.I spent approximately 12 years of my life with Russell's wife and their children;I wanted to help them so I gave up work. My finances crumbled and I withdrew from having a wide circle of friends.
- 59.1 told a couple of friends about the troubles in our lives and they have supported me dearly and continued to treat my family the way they did before I disclosed our secret. A friend of mine, Marlene, who I have known since I was aged 17, helped me organise all of the catering for Russell's funeral as she ran a pub at the time. I was in shock at this time and she showed me so much support which is a sign of a sincere friend. I am eternally grateful to Marlene.
- 60. However, on one occasion when I told another friend, whom I considered close, why Russell had passed away, she subsequently moved house and never provided me with any forwarding contact details.
- 61. When we were children, we were not allowed to tell anybody that my father was a Haemophiliac. When my sister, Dorothy, asked her teacher what a Haemophiliac was, the teacher was shocked that she even knew that word

10

and reacted as though the words' sole meaning was connected to infections. I remember our childhood as having to keep secrets and being restricted because of the horrible stigma that was wrongly associated with Haemophiliacs.

Section 6. Treatment/Care/Support

- 62. When Russell passed away, a counsellor came to our house to see me. She asked if I was feeling angry. I replied that I felt sad because my son has just died. Unbelievably, she then said "When Robert is gone, you will be able to grieve properly". I told her to get out of my house because her remark was extremely insensitive and wholly inappropriate. I believe that this situation deterred me from seeking counselling later on in my life.
- 63. Recently, just before the Christmas of 2018, the doctor offered me counselling. But I feel that I cannot change what has happened and I have to cope with it regardless and I need to find a way to get there. I do not think antidepressants would help me and I don't want to pop pills to "*cure*" something that can't be cured.
- 64. An example of some of the horrendous treatment that was shown to my father occurred on the John Waring Ward at the Churchill Hospital. He was given a huge, tough and mud covered jacket potato that was not fit for animal consumption. My father was too weak to pick up a knife and fork but no-one helped him. Luckily my mother was there and gave the staff a piece of her mind.
- 65. When the doctors treated my father they were always fully masked and gloved. He was also put in isolation wards which were freezing colds and had blinds which did not work.
- 66. He had dentures as a result of substandard dental care. Our local dentists would not treat him, and if they did, they did not treat him properly because he was left to his own devices to stop the bleeding and deal with everything

himself. If he had bled to death afterwards, they would have said that it was his own fault.

- 67. In relation to Russell, I recall that the medical staff and in particular Chris Conlan, would make horrible remarks such "*this guy will last about a week*" not realising that I was in earshot. I was speechless that he would discuss my son like that when he was taking junior doctors on ward rounds.
- 68. In relation to Robert; on one occasion he walked out of his room at the hospital during the night to go to the bathroom and there were lots of old radiators positioned directly outside his room which caused him to fall over and he knocked himself out. He called me at 2am to explain what had happened and said he needed Factor VIII. Robert probably suffered lots of unfair treatment from medical professionals but did not share this with me for fear of worrying me.
- 69. To the best of my recollection; Russell, Robert and Douglas were not offered counselling or psychological support.

Section 7. Financial Assistance

- 70. The Macfarlane Trust decreased my mother's widow's pension. We challenged this decision and in response we received a condescending letter from them. The application process was difficult and I feel that the Macfarlane Trust was a waste of time. A member of the Trust came to my mother's home to assist us but nothing materialised from this visit. I think they did this to keep themselves busy and in a job. We all recall that the staff employed by the Macfarlane Trust had a tone of superiority whenever we dealt with them on the telephone.
- 71. To the best of my recollection, my father received grants from the Macfarlane Trust for a washing machine, a bed and a mattress. I do not know exactly how much he received or when.

- 72. My mother received a payment of £20,000 from the Skipton Fund after my father passed away.
- 73. My son's wives dealt with their financial affairs so I do not know what financial assistance they received.
- 74.1 have not received any money from any of the Trusts.

Section 8. Other Issues/Conclusion

- 75. This is the first time I have ever been involved in an action of this nature. I have kept quiet for so many years; I have been forced to keep quiet.
- 76. We were not allowed to be involved in the 1991 litigation. We were never given an opportunity to fight for what we lost. We were never compensated for the injustice that happened; however, no amount of money could bring back my beloved father and sons.
- 77. What happened was a horrific tragedy. I want to know who authorised contaminated blood to be imported into the UK. I want to know who started the ball rolling.
- 78.1 want to know why the medical practitioners gave me contaminated blood to pump into my father and sons, without a word of caution. For so many years, I have blamed myself for their infections and for so many years I have put myself and my husband at risk of infection. What happened is both unfair and unspeakable.

Anonymity, disclosure and redaction

79.1 do not wish to apply for anonymity. I do not feel able to give oral evidence to the Inquiry.

Statement of Truth

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

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Dated 15 FEB 2019