Witness Name: DM Howton Statement No: WITN1669001 Exhibits: WITN1669002-3 Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DOUGLAS MICHAEL HOWTON

I, Douglas Michael Howton, will say as follows:-

Section 1. Introduction

- 1. My name is Douglas Michael Howton of GRO-C
 GRO-C

 GRO-C
 My date of birth is GRO-C

 Image: I have been married to Mary for 50 years and we have a daughter Vicky aged 40 who is a Head and Neck Cancer Senior Nurse.
- 2. I am one of 4 siblings (Julie Elizabeth Scott, Brenda Margaret Millard and Dorothy June Metcalfe), 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 15th June 1989, Russell on 5th October 1990 and Robert on 14th November 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 WITN1669002** 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.
- I am not absolutely certain when my father was infected with HIV or Hepatitis
 C. However, I have a very good idea that it was December 1984. At this time, Mary had collected the batch of Factor VIII in the early December which has been delivered from Oxford to Northampton.
- 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 believe that the GP thought that my father was already aware of his HIV status. 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. My father was an honourable, private man who worked hard all of his life despite being in dreadful pain approximately 80% of the time due to bleeds in his joints caused by Haemophilia. He was my hero, not because of any war, but the sheer effort of working in environments that were so destructive to his ill-health in order to provide for us; his family.

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 a brilliant man. He worked for me for a while and he never complained about the pain from his bleeds in his joints resulting from his Haemophilia. He was in excruciating pain. Russell was very genuine, honest, trustworthy, family-oriented, kind and considerate man. He never caused harm to anyone on this Earth and I loved him. He was another innocent victim.
- 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, 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.
- 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 Brenda that he was HIV positive, not knowing that she 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 WITN1669003 contains extracts from Russell's medical records which clearly demonstrate that medical staff have redacted copious amounts of information.

- 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-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.
- 24. Robert was never given any information about the risks of receiving Factor VIII.
- 25.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.
- 26. Robert was not given adequate information about how to manage his infections or regarding the risk of transmission. Robert tried his best to cope with his illness. He continued to work with his dad, Wayne Millard. Robert deteriorated years later; but he was still young. His walking became difficult and the illness had somehow affected his coordination and balance. Robert was a family man with 2 children. Robert had a granddaughter called **GRO-C** ho sadly passed away 3 years after Robert. It was a tragedy.

Section 3. Other Infections

27.1 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.

- 28. In relation to my father, I recall that his coordination deteriorated towards the latter stages of his life. Sometimes he would "*read*" the newspaper upside down. Furthermore, my wife 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 recall that he moved like a '*rag doll*'. He had no coordination and his muscles "*flopped about*".
- 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 recall 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 nephews 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

- 36. My father was riddled with illnesses towards the latter stages of his life. He was lethargic and fatigued which meant that he could not really live his life the way he used to prior to his infections. My father suffered with arthritis, poor mobility, emphysema, COPD and liver problems. He could not swallow towards the end of his life despite having an appetite which used to really upset my sisters and our mother.
- 37. My father was a good man with a lovely character which meant that we all noticed when he became depressed and introverted as a result of his infections and the AZT treatment which he had to endure. He felt devastated because the stigma relating to HIV at the time was very serious. He could not talk to anybody about his life and what was happening to him. I think he felt ashamed that he was infected with HIV because, wrongly so, of the type of people this infection was associated with. However, he was the most decent man I have ever known and will ever know.
- 38. My mother was remarkable in every way and particularly so when dealing with my father's care and medication. She would give him his medication at midnight and again at 6am and was always punctual. She wanted to keep him alive and after he passed, she had to take on the role of both a mother and a father. Physically, she was exhausted to the point that the bones in her feet had collapsed. I do not know how she coped mentally.
- 39. My mother and father were hard working people who did not deserve what happened to them. An example of my father's hard work was working extra shifts so that he could pay for me to go to college to study a full time building course. At the time, I was working in a shoe factory and my father wanted me to have a better life because he saw me as a bright individual and he wanted more for me than what he had achieved. After completing the building course I successfully obtained an apprenticeship. It was purely down to my father's perseverance and foresight that I succeeded.

- 40. My father was a wonderful man whom I looked up to and adored. I worked with him when I was a little boy and I know my father was proud of me. I was greatly affected by his infection and ultimately by his passing.
- 41. Before my father's infections, Mary and I would take my parents on holidays and I would describe this as a "*pure pleasure*". We both enjoyed treating them and Mary used to take my mother to M & S to get her some clothes, because throughout her life she had nothing. At the time when Mary and I had the money, we were able to make my parents' lives a little bit easier. They were always so grateful. But then our lives were ruined when my father passed away and we declared ourselves bankrupt. It took us a long time to recover. My mother then worked like a Trojan in vile jobs all her life to bring up her family. She went through having to cope with my father's infections and there were no benefits she could claim during those days. She was overwhelmed by grief and she never got over it. We were, and I believe that we still are, a close family and I believe that we have inherited our parents' work ethic.
- 42. Due to the stigma associated with HIV, we always lie about the cause of my father's death. We used to say that he had a brain tumour. People did not understand because they simply did not know the truth. It was a horror, and I believe that it still is.
- 43.1 have been severely depressed for many years. I became an alcoholic which has had a devastating effect on my own family. It led to me leaving my wife and daughter because I was unable to cope. It plunged me into absolute despair and my family lost me for a good few years. I know that I used to worry Mary to death because she would go out looking for me and was unable to find me. I would drink uncontrollably and find myself at the Kingsthorpe Cemetery, sobbing at my father's grave. It was awful for everybody.
- 44. This went on for years. I could not get over my father's passing which ultimately destroyed my life. It destroyed my relationship with Mary and Vicky.I lost our business and our home. But Mary loved me and wanted to look after me. When I walked away from them, Mary wanted to stay because she was a

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part of our family. Mary walked into my life when she was aged 15; Julie was 7 and Brenda was 21 so my sisters were like her adopted sisters. They were both absolutely marvellous to Mary. My mother and Mary were like a motorbike and a sidecar; their relationship was lovely.

- 45. At the time, I was not in a fit state of mind and I do regret wasting many years of my life. Those years damaged me and I know I can be difficult to live with. Mary describes me as a good soul and a genuine man. I am truly blessed to have Mary and our daughter in our lives.
- 46. My daughter Vicky idolised her 'pap'. He died when she was aged 11 and she was devastated as a result. She was very close to him and she used to stay with him when Mary took our mother out. She loved him as he did her.
- 47.1 currently suffer from severe COPD and heart failure; both of which have been contributed to by my heavy drinking. I struggled to come to terms with his death and I have still not managed this. My father was a private, honourable, family man who was innocent like all of the other people who have suffered and those that are still suffering today.

Section 6. Treatment/Care/Support

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- 48.1 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.
- 49.1 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.

- 50. 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.
- 51. 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.
- 52. 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.
- 53. On one occasion, I recall that social workers visited our family home and they acted as though the whole house was contaminated and as though the whole family were infectious.
- 54. As far as I am aware, neither my father nor my nephews were offered any counselling or psychiatric support.
- 55. I have never been offered any counselling or psychiatric support.

Section 7. Financial Assistance

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- 56. 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 a real pain and I feel that the Macfarlane Trust was a complete waste of time; the staff displayed tones of superiority and were particularly unhelpful.
- 57.1 believe that my father received grants from the Macfarlane Trust for a washing machine, bed and mattress.
- 58.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.

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- 59. I never received a penny from any of the Trusts and I was happy to hear that the Macfarlane Trust has now dissolved. My mother had to fight for any help and the endless arguments made her ill. They were all a group of disgusting people, a bunch of parasites who made a living out of our misery and treated us with contempt. Everything they did was means tested and it should not have been.
- 60. 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

- 61.1 am proud of my father, I am proud of Russell and I am proud of Robert. They were all so brave. They were innocents killed by arrogant people who thought they could "*play God*". I just pray we get justice for my family and all the families, whose lives were destroyed. They were all innocent people. The question on everyone's lips is "*why*?"
- 62.1 want justice and I want people to be named and shamed. I also want Kenneth Clarke to be questioned about this tragedy.

Anonymity, disclosure and redaction

63.1 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.

GRO-C Signed....

Dated 11-02-2019