Witness Name: KE Millard

Statement No: WIT1396001

Exhibits: WITN1396002-3

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KAREN ELIZABETH MILLARD

I, Karen Elizabeth Millard, will say as follows: -

Section 1. Introduction

- 1. My name is Karen Elizabeth Millard of GRO-C

 GRO-C

 My date of birth is GRO-C 1962. I currently work full time as a travel agent. I have a partner who is called Anthony and we have been together for five years. I have two children, Daniel and Samantha, and four grandchildren who keep me busy in my spare time.
- 2. I am an affected person in relation to my late husband Russell Wayne Millard, my late brother-in-law Robert Paul Millard and my husband's late grandfather Douglas Alfred Howton; 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.
- 3. 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 Russell:

- 4. 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.
- 5. Russell was infected with HIV and Hepatitis C as a result of receiving contaminated Factor VIII.
- 6. In or around the mid 1980's, I understand that Russell's mother 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.
- 7. 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.
- 8. I also remember that Russell and I attended the Churchill Hospital for a routine appointment when I was pregnant with Samantha, which was in 1986. I recall that Mary Fletcher, who was one of the nurses, told Russell and me that he was HIV positive. I had no idea what HIV was and we received no further information in this regard.
- 9. 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.

- 10. 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.
- 11. Exhibit WITN1396003 contains extracts from Russell's medical records which clearly demonstrate that medical staff had redacted copious amounts of information.

In relation to Robert:

- 12. 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.
- 13. Robert was told that he had HIV by Dr Rizza at the Churchill Hospital in the latter part of 1986, which was when 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.
- 14. Robert was never given any information about the risks of receiving Factor VIII.
- 15.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.
- 16. Robert was not given adequate information about how to manage his infections or regarding the risk of transmission.

Section 3. Other Infections

- 17.I believe that Douglas, my husband and his brother were definitely put at risk of vCJD and I believe that they all developed vCJD and I set out below why I believe this.
- 18. In relation to Douglas, I distinctly remember that his coordination deteriorated towards the latter stages of his life. Sometimes he would "read" the newspaper upside down.
- 19. In relation to Russell, I vividly recall that he moved like a 'rag doll" towards the end of his life. His muscles had gone totally limp and he was unable to hold himself up. He had no coordination and it was a shocking to witness.
- 20. Russell's death certificate records that he passed away due to encephalopathy and this further persuades me to think that he definitely had vCJD.
- 21. 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.

In relation to Douglas:

- 22. Russell's grandfather 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 WITN1396002** is a copy of Douglas' 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".
- 23. Douglas was never given any information or advice regarding the risks of receiving Factor VIII.
- 24. He received treatment at the Churchill Hospital, Oxford and his consultants were Dr Rizza and Dr Matthews.

- 25.1 do not know when Douglas was infected with HIV or Hepatitis C.
- 26. Douglas' wife opened a letter from the Churchill Hospital which was addressed to Douglas and was dated in or around November/December 1985. This letter advised that Douglas was HIV positive. It also enclosed raffle tickets for purchase.
- 27. Douglas' wife did not advise him about the contents of this letter but she did tell her children and asked them not to tell anyone; least of all Douglas. His wife wanted to protect Douglas because she knew that he would worry about such a diagnosis.
- 28. In any event, some months later Douglas 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 Douglas "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, the GP obviously thought that Douglas was already aware of this diagnosis. Douglas returned from this appointment and did not tell his wife; not realising that she already knew.
- 29. Douglas was not given any information about how to manage the infection and he was not provided with any information regarding the risks of transmission.
- 30. Douglas was also infected with Hepatitis C but he was never told that he had this infection.

Section 4. Consent

31.1 strongly believe that my Douglas, my husband and his brother 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.
- 33.Both Russell and Robert received Hepatitis B vaccines without their knowledge and therefore impliedly without their consent.

Section 5. Impact

In relation to Russell:

- 34. Russell was such a loving and kind man who would do anything for anybody. When Russell found out that he was HIV positive he disintegrated into a shell of his former self. He became angry and distressed. He almost gave up overnight because he correctly predicted that HIV was a death sentence.
- 35. Russell struggled mentally; he was so scared because he knew that he would not see our son Daniel growing up. Russell did everything by the book and it was so unfair that he had to endure the path before him. Russell was upset and completely devastated that he would not see his daughter Samantha and his son Daniel grow up.
- 36. He had witnessed first hand how his grandfather had suffered with HIV and this made him very depressed as he could see very clearly that his life would follow the same trajectory. He also carried out his own research to ensure that he was equipped with as much information as possible in relation to this cruel virus.
- 37. Russell's mental health deteriorated but he dealt with his negative feelings alone. He did approach his GP on one occasion and was offered medication but he declined this. As he approached the latter stages of his life, he was engulfed with an extremely sad and negative outlook which was so upsetting to see.

- 38. Russell suffered from a number of medical complications in the year leading up to his passing. He experienced terrible fevers, chicken pox, seizures, appendicitis and extreme fatigue.
- 39. One of the visions that remains etched in my memory is a photograph of Russell at our son, Daniel's christening. Russell looked so gaunt and ill. The person in the photograph was a completely different person to the Russell I had known; his hair had fallen out and he was emaciated. My poor Russell used to disguise his weight loss by wearing baggy jumpers.
- 40. Russell hated the hospitals and doctors; it was like he knew that they against him. I recall sleeping on the hospital floor, next to Russell's bed, to try and comfort and care for him. Russell thought that every hospital visit would be his last.
- 41. We struggled financially. Russell used to work for his father and he was understanding when Russell was particularly poorly. However, towards the latter stages of Russell's life he was unable to work and I therefore went out and sought any type of work I could find just to keep the money coming in.
- 42. The financial struggle was exacerbated following Russell's passing and I sought and held down three jobs so that I could keep a roof over mine and the children's heads. It was only about five years ago that I was able to drop back down to having only one job.
- 43.I have had a number of abusive and unhappy relationships since Russell's passing. However, this all changed when I met Anthony around five years ago. He was the first person to make me laugh and smile after a very dark period following Russell's passing.
- 44. Following the commencement of the Public Inquiry I have found it a little easier to start to discuss what happened to Russell with others. However, I have struggled for years because we were unable to speak out due to the stigma surrounding these viruses. I feel that I have suffered by having to keep everything bottled up inside me for so long.

- 45.I loved and supported Russell in the best way that I could and I constantly worried about him. I was also fearful of the fact that I was going to be a single mother and that my children would not get the chance to meet and get to know their fantastic father.
- 46. Another memory etched in my mind which causes me immense distress is the way in which the funeral directors treated Russell and our family after he had passed away. A number of funeral directory openly stated that they were not prepared to deal with my loving and loyal husband due go his HIV status.
- 47. Finally we managed to secure the services of one funeral director and they put my Russell's body in a bag and sealed it. I was unable to say goodbye to him and my last memory of his is of him being in a sealed bag. The funeral directors' conduct was inhumane and I was extremely distressed by such behaviour.

Section 6. Treatment/Care/Support

- 48. Russell had appendicitis in or around 1989/1990 and the doctors treated him as though he had the plague. He was taken by ambulance to the John Radcliffe Hospital and admitted to an isolation ward. Medical staff were fully gloved when dealing with him.
- 49. When I was pregnant with Samantha I was also placed on an isolation ward and I was treated as though I was infectious. During this time I was being tested for HIV, but unlike the Haemophiliacs, I was aware of this fact.
- 50. Russell was never offered any counselling or psychiatric support and following his passing I was not offered any such support.

Section 7. Financial Assistance

51. Russell received financial support from the Macarlane Trust. I think that he received an initial payment of £20,000 and then a further payment of £40,000. I recall that we set up trust funds for our children at this time.

- 52. Following Russell's passing, I received a widow's allowance which was paid to me on a monthly basis. This was means tested and I had to provide detailed evidence of the state of my financial affairs. I was initially impressed with the Trust but as time went on my impressions changed somewhat. I really struggled when the children were young and the trust fell far short of what I would have expected in terms of even providing some sort of basic assistance.
- 53. Initially Russell did not receive a penny from the Skipton Fund and following his passing I was also let down by them. It was not until last year after so much fighting that I finally received the £20,000 Stage 1 Payment for Russell's infection with Hepatitis C. Russell and I had been denied this payment for years as we had no proof of him being infected with Hepatitis C due to the "missing medical records".
- 54.I had to move in with my mother and father because I was struggling financially. The Skipton Fund, when assessing whether I was eligible for support, took into account my mother and father's pensions and therefore denied me any financial assistance. I am therefore of the view that the Skipton Fund was not fit for purpose.

Section 8. Other Issues

55. My son, Daniel, is a member of the Tainted Blood Support Group, the Fatherless Generation and the Contaminated Blood Campaign Group. He is able to find out information and pass this onto me and I feel supported in this way. These campaign groups keep us abreast of current developments.

Conclusion

56.1 want justice for Russell and I want the people responsible for this tragedy to be named and shamed. At the end of the day, these people murdered my loving husband and I want answers.

Anonymity, disclosure and redaction

57.I do not want to apply for anonymity and I do not wish to give evidence to the Public Inquiry.

Statement of Truth

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

GRO-C Signed.

Dated 2

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