Witness Name: RICHARD KELLETT-CLARKE
Statement No: WITN1323001
Exhibits: WITN1323002
Dated: APRIL 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RICHARD KELLETT-CLARKE

I, Richard Kellett-Clarke, will say as follows:-

Section 1. Introduction

1. My name is Richard Kellett-Clarke. I was born on GRO-C 1954 and I live at GRO-C Hampshire GRO-C. I am married with two grown up daughters. I previously owned and managed a software company and I am now retired.

2. My twin brother, Roger Grenville Quentin Clarke (born on GRO-C 1954), was infected with the Hepatitis C Virus (HCV) from contaminated blood products. My different surname to that of my twin brother, Roger, is the result of my marriage to Frances 31 years ago. I am a Haemophiliac like Roger. Roger died from liver cancer on 18th May 2003, aged 48.

3. This witness statement has been prepared without the benefit of access to my brother's medical records. Roger had a limited number of medical notes and records (in the possession of his then solicitors when he died). The relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. Roger had Haemophilia A (1-2%).

5. I believe that Roger was infected by what I also believe was an unnecessary Factor VIII (FVIII) injection in 1976/7 while being treated at the Royal Infirmary in Glasgow for renal colic. Roger was an active, healthy, amateur pilot, accountant, who drank in moderation as he was almost teetotal, but a mild smoker (<20 a day). Although married he had no children which in part may have been because of his health/haemophilia status.

6. Roger contracted HCV from a FVIII injection and went on to develop liver cancer after the HCV went untreated. The liver cancer (3cm in diameter) was detected on 7th December 2000, not by any NHS process but the result of a job related insurance medical. In spite of it being operable at that time it was left and it took close to three months of tests for him to prove he was eligible to go on the transplant register, and two weeks to find him a donor liver. Due to this delay the growth in his liver was as large as 6cm in diameter when his liver was transplanted and, again, he was left untreated post liver transplant. He could and should have been given adjuvant chemotherapy. Following on from that he contracted secondary bone and brain cancer and died two years later.

7. Roger was not infected with HIV or HBV nor did he have cirrhosis of the liver through excessive drinking as he led a reasonably healthy lifestyle and had regular medicals as an amateur pilot.

8. Roger was treated in the Royal infirmary in Glasgow and, subsequently, monitored and treated by the Oxford Haemophilia Centre (OHC) at the Churchill Hospital and the Oxford John Radcliffe Hospital respectively. He was again treated for bouts of rental colic with FVIII concentrate in 1980 and 1984. I do not know for sure which incidence of Factor VIII caused him to be infected (and neither did Roger). He was under the care of Dr Rizza and Dr Matthews initially and then Dr Giangrande at the OHC. His liver transplant was carried out by University Hospital Birmingham.

9. When Roger was given contaminated blood concentrate, in his mid to late twenties, he was effectively handed what was a sentence of poor quality of life, followed by an agonizing death. Despite morphine Roger had to endure a painful death that I had to watch happen without any support for either of us.

10. Roger first tested HCV antibody positive in 1991 but he was not told about it or offered any support or treatment. At the very least he should have been appropriately assessed/monitored every four months as patients should in accordance with the 1995 NHS guidelines and protocol. Roger felt very let down that he was not alerted to the problem in 1991 (or sooner).

11. Roger was informed of the diagnosis by Dr Giangrande in September 1996 but, even then, he was not offered any treatment nor was the implications of having the infection explained properly to him. No adequate information was provided and no action taken until the cancer discovery in 2000. Information about risk should have been given to him and action taken as far back as 1988. His progress should have been monitored and various treatment options discussed with him.

12. Being infected by contaminated blood concentrate contributed to the destruction of Roger's marriage, so much so that GRO-C GRO-C was ill, and I gave up work to look after him by driving from Southampton every other day to Oxfordshire in 2002/3 until he died at home on the 18th May 2003.

13. When Roger died, he did not have a full appreciation of just how badly he had been let down by the Government as well as the NHS. I think he took the view, as did I, that the contamination of the FVIII concentrate was bad luck. He did not know that the FVIII was *known* to be contaminated and that nothing was done about it. His primary issue of concern was in finding out that the FVIII administered to him was not strictly needed for renal issues as well as the negligence/catalogue of errors made in his care (or lack of it) after contracting HCV.

Section 3. Other Infections

14. Roger did not receive any other infection. I know that he was tested for HIV and the test returned negative.

Section 4. Consent

15. I believe that Roger was tested for HCV without his knowledge or consent and without being given adequate information about possible risk of having contracted HCV through contaminated blood products.

Section 5. Impact of the Infection

16. Roger and I grew up in Scotland. We both had negative experiences of having haemophilia, in being poked and prodded, for the best part of our lives and later rejected for jobs we had applied for. We distanced ourselves from the Haemophilia Society and kept haemophilia status to ourselves. We learned to adapt without treatment and spent our time trying to avoid injury and/or complication. The physical restrictions for Roger meant he was too tired to do lots of things and confined himself to singular hobbies and things he could do on his own. His greatest love in life was flying.

17. Roger developed renal issues resulting in him being treatment with FVIII in 1976/7, 1980 and 1984.

18. Roger was only told that he had HCV by Dr Giangrande at OHC in 1996 despite having been tested HCV antibody positive as early as 1991. I refer to **Exhibit WITN1323002** being the report of Dr John O'Grady dated 9th April 2003 instructed on behalf of Roger in considering an actionable claim against the Oxford Radcliffe Hospitals NHS Trust before Roger died. Dr Trowell (Consultant Hepatologist at the John Radcliffe Hospital) is criticised by Dr O'Grady in failing to request HCV testing on clinical grounds and failing to make an HCV diagnosis during the period 1992 to 1996.

19. Roger's quality of life took a downwards spiral when he was diagnosed with liver cancer. The strain he was under affected his behavior GRO-C. It was a significant, contributory factor in the breakdown of his marriage. His new liver failed and he succumbed to secondary bone and secondary liver cancer two years post-transplant. With the progression of his illness his flying was taken away from him. He had no energy and lost the ability to walk too far and had difficulty in concentrating. I tried to keep his spirits up in trying to organise things of interest I knew he had always wanted to do. The bone cancer behind his eye began to distort his face as it grew. My brother was destroyed by what happened to him and it took him 15 months to die and it was a horrific time.

20. Roger suffered from depression. He began to turn inwards and there was a constant sadness in him. The infection itself and knowing that there had been several missed opportunities for medical intervention by the NHS to save and/or prolong his life, had a huge psychological impact on him. When my brother was advised that his claim against the NHS was at that time going to be too difficult to pursue, he lost all motivation to keep going and passed away within a fortnight.

21. For me personally, it took two years out of my life at a most important time in my career, resulting in me struggling to get back into full time work afterwards. It was a complete torture for me to drive nearly 190 miles every other day to sit with Roger and see him decay; watch his face and body distort and to see him in such pain and yet helpless to do anything. Mentally I have never recovered from his death and I have never been able to talk to anybody about it. To lose your twin, the only true friend in your life and the person who is so close to you they can finish your sentences and know what you are thinking before you say it, is an indescribable loss.

22. Roger's death had an indirect impact on my marriage as my GRO-C GRO-C GRO-C GRO-C. My children were away at school but they GRO-C.. The loneliness I feel at the loss of Roger and my GRO-C

GRO-C had a large, irrecoverable impact on my marriage. I constantly torture myself with the question of whether I could have done more for him if I had known sooner what Roger was up against.

Section 6. Treatment/care/support

23. Roger was not treated for HCV or for cancer.

24. Roger was found to have cirrhosis of the liver, but to add to the distress of his ordeal he was treated (by Dr Trowell) as though he had brought the condition on himself through alcohol abuse. Despite the lack of evidence to the contrary, Dr Trowell refused to believe Roger was akin to being a teetotaller. He came up against resistance in being put forward for a new liver. Dr Trowell refused to refer Roger as a suitable candidate for treatment until he had undertaken and passed a series of four or five tests. The tests were not conducted together but in turn (each test involving three stages of appointment, then test and result) creating unnecessary delay. The delay from the date of the scan up until the transplant resulted in a further 3 cm diameter growth of the carcinoma.

25. No counselling or psychological support was ever offered.

Section 7. Financial Assistance

26. Roger was not provided with any financial assistance from any of the Trusts and Funds set up to distribute payments.

27. I have not received any financial assistance in relation to my brother

Section 8. Other Issues

28. My brother lived in fear all his life that the prejudice he experienced as someone with haemophilia in his twenties would be magnified and he would become

unemployable. This is why he tried to become self employed which led (at the insurance medical) to the discovery of the cancer that killed him.

29. I have myself struggled with haemophilia. It has impacted on my job/career prospects and the way in which people integrate with me. The associated stigma in how you are viewed and the assumptions that are made about you is alive and well even now. No-one takes a risk on someone they don't have to. I have chosen to speak about it openly to the Infected Blood Inquiry because I am devastated by what has happened to my twin brother and how he has been treated. I cannot get over the fact that nobody understood or properly considered the consequences of their actions when haemophiliacs were treated with contaminated blood and that the NHS system is so impersonal and focused on protecting itself from legal liability that it lost sight of the infected human at the centre of all of this.

Anonymity

30. I confirm that I do not wish to apply for anonymity and that I understand this Statement will be published and disclosed as part of the Inquiry. I am willing 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 20/4/19.

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This witness statement has been prepared without the benefit of access to my full medical records. .

1. First treated with factor VIII in the Royal infirmary in Glasgow for renal colic	1976/77
2. Moved to Oxfordshire	1978
3. Treated for bouts of renal colic with factor VIII	1980 & 84
4. Identified as having abnormal liver function	June1988
5. HCV antibody positive *(flow charts and summary sheets)*	Jan 1991
6. Abnormal liver function (Gamma GT 552 iu/l, AST 188 iu/l)	Feb 1991
7. HBV vaccination	1991
8. Reviewed at clinic and noted to be jaundiced	14/1/1992
9. Improvement in jaundice noted	Feb 1992
10. 'Not thought to be jaundiced'	May 1992
11. Laparotomy (liver described as normal in appearance) Development post-operatively ascites NB Roger was told of the presence of liver damage "similar to that caused by alcohol"	6/10/1992
12. Ongoing fluctuation in liver function	1992-96
13. HCV positive *(flow charts and summary sheets/ not verified as clinical notes missing)*	Mar 1993
14. Noted to attend clinic of Dr Joan Trowell (Consultant Hepatologist) on a number of occasions	1993-95
15. HCV positive *(flow charts and summary sheets/ not verified as clinical notes missing)*	Jan 1996
16. HCV positive *(Clinical Notes)*	27/5/1996

17. Informed of HCV diagnosis by Dr Giangrande but no treatment was offered	Sept 1996
18. Diagnosed with aggressive liver cancer (operable 3cm)	7/12/2000
19. Liver transplant	Mar 2001
20. Operation to remove secondary bone cancer behind his eye	End 2002
21. Died aged 48	18/5/2003