Witness Name: Graham Charles Russell
Statement No: WITN3261001
Exhibits: WITN3261002-04
Dated: 25th June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRAHAM CHARLES RUSSELL

I, Graham Charles Russell, will say as follows:-

Section 1. Introduction

1. My name is Graham Charles Russell of GRO-C Denmark. I was born on GRO-C 1954. I am a Chartered Psychologist and I worked for 23 years as an academic psychologist and researcher at a British University before moving to Denmark with my wife of 35 years. We have two children and three grandchildren.

2. I make this statement in relation to my late brother Malcolm Alexander Russell (Malcolm) who was born on the GRO-C 1956 and sadly passed away on the 12th March 1990 aged only 33 as a result of receiving contaminated blood products.

3. Malcom was an extraordinarily resilient human-being that was incredibly unlucky in being born with Haemophilia and then contracting AIDS; although I do not

think that luck had much to do with the latter. Certainly, he believed that hose in authority had been negligent and that not enough was done to prevent and alleviate a human catastrophe by sourcing blood products from populations associated with a high risk of HIV and Hepatitis B.

4. This statement has been prepared without the benefit of access to Malcolm's full medical records.

Section 2. How Affected

5. We used to live in Scotland and I recall that we were on holiday in Deal in Kent when Malcolm was about 18 months old and became very poorly. We had to travel to a hospital in London to enable him to receive treatment and he was diagnosed with severe Haemophilia A. Thereafter he often suffered from internal bleeding and complications with his joints and tendons.

6. At first he was treated with blood transfusions at the Royal Infirmary in Edinburgh throughout his childhood. My parents moved to the far north of Scotland where my father was employed as civil engineer at GRO-C As a family we made frequent trips to Edinburgh for Malcolm to be treated for Haemophilia-related conditions.

7. When I was about 13 years old we moved to GRO-C so as Malcolm could attend the Oxford Haemophilia Centre at the Churchill Hospital (OHC) which was a renowned treatment centre that offered home treatment. This treatment allowed Haemophiliacs like Malcolm to self-administer Factor VIII clotting agent, which could be used to prevent or minimise the effects of internal bleeding. This revolutionised care and greatly improved his quality of life. During this period, up until his untimely death, he was predominantly under the care of Dr Charles Rizza.

8. Malcolm was around eleven years old when we moved to GRO-C near GRO-C and he commenced the home-treatment programme. He was treated with Factor VIII until he died.

9. As far as I am aware, my parents were not provided with any advice or information beforehand about the risk of being exposed to infection from blood products.

10. As a result of receiving contaminated blood products Malcolm was infected with HIV and Hepatitis B (HBV).

11. After Malcolm died contemporaneous notes, draft letters and letters have been found in his possessions which I will refer to in this statement and exhibit.

12. Malcolm recorded in his diary that the date of his first positive test was the 3rd October 1984; he would have been 29 years old. However, the diary notes state that he was told he was HIV positive on the 1st August 1985. I do not know who told him, but it is very likely to have been Dr Rizza. I also do not know the details regarding when or from whom Malcolm found out that he was infected with HBV. He was being treated with Factor VIII supplied by Armour according to his notes.

13. Malcolm wrote in what appears to be an undated draft letter to the General Secretary of the Haemophilia Society (the draft letter) that *"I had one letter to recall a batch and then on the 6.10.86 a phone call at night from the unit* [the OHC] *to say could I return my batches issued on the 27/07/86 Batch no's which I have."* From the content of the letter the date seems to be sometime in 1987. Then in Malcolm's diary he says *"6.10.86 17.45 Dr Matthews rang two faulty batches supplied Armours detecting system not up to scratch batches recalled, 2 late 16 of 20 bottles issued already used. Batch no's A40510 issued on 27/7/1986 (Negligence must complain strongly to Matthews Friday 10th)".* I question how they knew they were faulty.

14. There is now produced and shown to me marked Exhibit WITN3261002 an undated letter from Dr Rizza, although it is, I believe, dated June/July 1985, this appears to be before he was told he contracted HIV. In the letter general advice was provided about health precautions that Haemophiliacs should take. This must have been disturbing for Malcolm and he would have suspected even more strongly that he had been infected. The letter states: "*Avoid contamination of work areas with patient's blood and clean any blood-stained area with an antiseptic. Thoroughly wash or boil where reasonable blood-stained handkerchiefs. Do not leave blood-stained needles unguarded. Report any accidental stab injuries with dirty needles*".

15. In the draft letter Malcolm confirms that "*No advice on sexual safeguards till Aug 85*". By this he is referring to Exhibit WITN3261002 which also states "*In the case of adults it is advisable to use a sheath during intercourse*". To my mind the advice and information given in relation to safeguarding or prevention was cursory and not given till June or July 1985 and I think it indefensible that safeguarding information was not provided to Haemophiliacs and their families sooner, especially as it appears the OHC strongly suspected as early as 1983-4 that Haemophilia patients were at risk for HIV and hepatitis B and started some form of monitoring programme and an apparent programme of testing for HIV and hepatitis B, which is referred to in the letter and I will refer to below.

16. Although Exhibit WITN3261002 refers to wearing condoms, there was in my opinion inadequate information provided in relation to risk to others such as Malcolm's wife and son. The letter was somewhat impersonal, cursory and ad-hoc. The standard practice in events where a diagnosis of severe illness is made is to provide information in relation to sources of possible internal and external support. There was no support or ancillary information supplied in the letter from Dr Rizza.

17. I consider that information about infections should have been provided to Malcolm as early as 1983. I believe the hospital knew there was certainly a problem but information regarding keeping safe was not relayed to the haemophiliacs until much later or in some cases not at all and I question why.

18. Malcolm visited me in GRO-C during, I believe, the bank holiday weekend in August 1985. We went out for a walk and he told me that he had been infected with HIV. We were both upset but I think he tried to play down his diagnosis and told me he could take medication to manage the virus.

Section 3. Other Infections.

19. I do not know whether Malcolm was exposed to vCJD.

Section 4. Consent.

20. I believe Malcolm was treated, tested and used for the purposes of research without his knowledge and therefore impliedly without his consent.

21. The letter at Exhibit WITN3261002 states that by the time of the letter (June/July 1985) they "*have now tested about 300 patients, some only once or twice, some as often as five or six times*". The sheer logistics involved in longitudinally testing 300 patients suggests that testing took place over a protracted period of time. Dr Rizza appears not to tell Malcom why the tests were being carried out. I would like to point as a professional academic and researcher, that the principle of *informed consent* exists to protect participants from harm and to ensure that participants are fully aware of why the research is being carried out, including its goals and its methods. In addition, researchers must seek ethical approval from an independent and expert body and the purpose of this is to ensure the principle of beneficence, meaning that the goals and methods of research employed do not conflict with the best interests of the participants. It is not enough to simply

believe that the ends justify the means. In Malcolm's case, I wonder whether the research conducted on him and other Haemophiliacs at the OHC may have conflicted with a duty of care, particularly with regards to early advice to patients and their families about possible risk from HIV and Hepatitis B.

22. In the draft letter Malcolm says "*in August 1985 I was told that 10 tests had been done six were without my knowledge*".

23. There is now produced and shown to me marked Exhibit WITN3261003 a draft letter addressed to Mark Mildred at Pannone Napier Solicitors in which Malcolm refers to an "immunity *survey which I agreed to. This was started in October 84….. to see if there was a possible risk to Haemophiliacs*".

24. The notes Malcolm made in his diary refers to a number of tests as follows which could be the immunity tests:

- 3/10/84 start tests at Churchill for Aids tests - 2 years
- Hepatitis B Pos July – Oct 83
- Started heat treated factor eight end of Dec 84
- 15.1.85 2nd tests for Aids immunity (skin tests)
- Also 3rd Blood test for new heat treatment material
- 16th July 4th test + 6 monthly check up
- 17th Oct 85 5th test
- Immunity Survey positive last 9 months
- 13th February 86 6 test HVTL3 positive last 12 months
- 5th June 7 test HTVL.

25. I believe there was a known problem with contaminated blood products at the OHC possibly with an ongoing programme of testing. OHC appears to have been concerned about contaminated blood products from the supplier Armour, but they seemed not to have disclosed this to their patients until the point when many

were already infected. This is also supported by the fact that batches of Factor 8 were being recalled.

26. Dr Rizza held a post of Medical Research Council and published several research papers including "*Time from infection with HIV to onset of AIDS in patients with Haemophilia in the UK*" (Stat Med. 1990 Jun;9(6):681-9). Additionally, as a clinical research fellow at the Blood Coagulation Research Unit in 1990, he conducted research on how long it took haemophiliacs to develop AIDS.

27. The letter at Exhibit WITN3261002 suggests quite clearly many tests have been undertaken on many haemophiliacs. The letter concludes "*It is important that we should repeat this test from time to time and I hope you will be willing to continue to collaborate in this work*". The wording of this letter suggests to me that a programme of research was underway. In addition, It should be noted that this 'offer to take part' falls very far short of the criteria for informed consent.

Section 5. Impact

28. When Malcolm told me that he had been infected with HIV he was upset but he tried to gloss over the news of the virus. By the time HIV had progressed to full blown AIDS he was devastated. He had lived with Haemophilia his entire life which had made him a resilient man, but he became bitter and he felt very let down. He had implicitly trusted the doctors who provided care and would have developed a close, intimate relationship with them over the many years. In particular with Dr Rizza in particular who was Malcolm's consultant over a long period of time. I think he felt that he had not been straight with him and the dissolution of trust would have been psychologically devastating. The wider issues as to why the blood had not heat-treated had a crumbling effect on Malcolm's mental well-being and he clearly became angry and resentful of his circumstances.

29. Physically Malcolm was not suffering too badly from HIV at the outset of his diagnosis. However, later on as the illness developed into AIDS, he started experiencing severe physical problems related to impaired immunocompetence. He developed systematic and unpleasant thrush and was exposed to cryptosporidium infection via tap water. In healthy people, this parasite causes short-lasting and unpleasant diarrhoea and vomiting, but in immune-supressed people with AIDS, the parasite may become rampant and destroy the liver, causing severe and uncontrollable symptoms that ultimately lead to death through wasting and dehydration.

30. Malcolm was hospitalised for terminal care when his liver started failing.

31. I am unaware as to the precise date of when I found out that Malcolm's HIV had developed into full blown AIDS. I certainly knew by May 1989 when I was in my final year of my degree at GRO-C University, because I lodged a claim for *extenuating circumstances*, in case the circumstances interfered with my ability to complete my studies. However, I believe that Malcolm must have been aware about the progression of his virus beforehand.

32. Malcolm was admitted to an isolation unit at Churchill Hospital around 5 weeks before he died. When my wife and I visited him, we found him in a toilet in a distressed state plastered in diarrhoea. He said he had been there for a long time and nobody had been in to check on him. Following this sad incident, I filed a formal complaint and had a meeting with the Chief Nursing Officer. It was obvious that nurses were fearful and scared of AIDS and, most likely, avoided patients. Following this incident, we made the decision to provide terminal care Malcolm at home as a family. Primarily because we had lost trust in the care offered at the hospital, which was in fact abhorrent.

33. Malcolm died on the 12th March 1990. He was 33 years old.

34. There is now produced and shown to me marked Exhibit WITN3261004 the Coroner's Inquisition dated 22nd March 1990 which states the causes of Malcolm's death as being: 1a. Bronchial Pneumonia, 1b. Cryptosporidial infection, 1c. HIV infection and haemophilia. The document records that Malcolm contracted HIV "*as a result of being given contaminated blood products*" and goes on to say "*he died as a result of an accident*". This of course goes to the nub of the matter. Was his death really accident? I don't believe so for a moment. Had he not contracted HIV/AIDS he would not have died of Cryptosporidial infection. It is a simple and as brutal as that.

35. I am unsure as to the treatment Malcolm was given to manage his HIV infection. He took a variety of pills including AZT which involved approximately 5 or 6 pills every day to supress the HIV and to stop it from developing into AIDS. In the present day medical practitioners know how to effectively manage the infection, but back then it was all pretty much trial and error.

36. I do not know whether any other treatment was available for Malcolm. The availability of medical treatment for HIV was not something that Malcolm ever raised to me as a concern.

37. Malcolm was worried and fearful about many things, including his own health, the future security of his wife and son and the need to keep his HIV/AIDS a secret from all but close family. I think he also suffered from depression and a sense of abandonment. He had lost trust in the doctors at the OHC and lost trust in the Haemophilia Society, whom he felt were not sufficiently rigorous in pursuing the government and the NHS for negligence in importing blood products from known high risk groups. This would have been psychologically devastating for him and it is difficult fully appreciated the feelings of abandonment that he must have experienced.

38. My mother was impacted by the loss of her son. Although she has never sought help, I believe she has suffered from GRO-C and her pleasure in life was destroyed. From a professional perspective complex GRO-C is common in mothers who lose a child. Recovery often requires professional help as having a supportive family is invaluable but often insufficient in itself.

39. I know that Malcolm felt that having HIV/AIDS meant that he had no future and limited prospects at work, no prospects of getting a mortgage or further education. Early on, when first diagnosed with HIV, he was very grateful when he was accepted for a job at the local council., However when his symptoms became evident he had to give up his job, which resulted in severe financial difficulties and fear about the security, well-being and future for his wife and son who would have only been a toddler when Malcolm was diagnosed. It was extremely difficult for the family.

40. Due to the everlasting stigma surrounding HIV, Malcolm's son Jeremy only recently found out the truth about his dad's real cause of death. As a result of the Inquiry commencing the family felt it would be important for Jeremy to benefit from giving a witness statement should he wish to do so. At the time when Malcolm was diagnosed with HIV and after he had passed away, there was so much hysteria around HIV which led the family to keep secret Malcolm's infection and cause of death. Only the immediate family were privy to the truth and his close friends thought he passed away of Haemophilia related illnesses.

41. I believe that the AIDS hysteria which existed at that time can be laid firmly at the doors of the government which launched a health promotion campaign with giant posters containing apocalyptical images of coffins and death that were designed to inject fear into the homosexual community in an attempt to stop them having sex. The campaign was widely regarded as a total failure and did not change the behaviour of the homosexual community, but it did however, inadvertently

succeed in causing mass hysteria, so that the general public feared being contaminated with AIDS via normal everyday contact, like shaking someone's hand or sharing a toilet. The net result of this was that anyone with a diagnosis of AIDS was shunned and socially ostracised, including of course, haemophiliacs.

42. From a psychological perspective social support is one of the most important mediating factors in helping cope with adverse circumstances. Malcolm's immediate family had to keep his illness and eventual cause of death a secret. As a consequence, the normal forms of social support that might have been available to the family in coping their grief and in, in terms of his wife, practical support, was not available either.

43. At the stage when Malcolm was terminally ill we nursed him at home as a family, although I was only there for the final days. His death was gruesome, purely and simply, and I found myself traumatised. Not so much at the time, because I was involved in the practical element of nursing care, but later on, as the reality of the situations sunk home, I found myself experiencing a deep hostility and resentment towards the '*men in grey suits*', whose attitude was to save money with scant regard for Malcolm's wellbeing and all the other parties affected. I feel a continued sense of bitterness, which has caused problems for me in my career, when confronted with authority figures.

44. I believe that many families of haemophiliacs will also have been traumatised with long lasting effects. As children we grow up with a '*just world belief*' which we carry into our adulthood. This belief reassures us that if we play by the rules and do the right thing, no harm will come to use. It is one of the ways in which we cope with the realities of what can be a very harsh world. When people are traumatised, the belief is shattered. The bubble is burst and they come to experience existential angst and worry that dreadful things might happen at any time. I have found myself, experiencing this and it plays out when I see my

grandchildren. I tend to imagine all the horrible things that might happen. It's really quite unsettling.

Section 6. Treatment/Care/Support

45. No psychological support or help was offered to Malcolm or to our family.

Section 7. Financial Assistance

46. Malcolm wrote a letter to the Haemophilia Society around the time he knew he was infected requesting support. I believe this request went largely unnoticed. In the later years his wife received a sum of money but I am not privy to how much she received.

Section 8. Other Issues

47. There was clearly a known problem with contaminated blood products at the OHC with an ongoing programme for HIV testing. The practitioners involved at the OHC and elsewhere must have been concerned about employing contaminated blood products from Armour, but appear not have openly disclosed their concerns to their patients until the point at which many had already been infected. This is also supported by the fact that batches of Factor VIII were being recalled. One has to wonder why?

48. I believe that if the families of haemophiliacs infected with HIV, AIDS and Hepatitis are looked at it will be seen that many people have been directly impacted with varying degrees of psychological distress quite possibly of a chronic nature. In this, I include wives, children, mothers, brothers and sisters. In stating this, I am thinking of complex, unresolved grief and Post Traumatic Stress Disorder (PTSD) flowing from the shattering of the aforementioned '*just world*

beliefs'. Moreover, we now know that the effects of psychological distress are not restricted to the mental arena, but are associated with an increased risk of chronic physical health problems including auto-immune diseases and heart disease.

Section 9. Anonymity, disclosure and redaction

49. 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.

50. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

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

GRO-C

Signed...

Graham Charles Russell

Dated: 25th June 2019