

**Witness Name: Lynda Walker**

**Statement No.: WITN3216001**

**Exhibits: WITN3216002**

**Dated: 29th August 2019**

### **Infected Blood Inquiry**

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#### **WRITTEN STATEMENT OF LYNDA WALKER**

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I, Lynda Walker will say as follows:

##### **Section 1: Introduction**

1. My name is Lynda Walker and I reside at GRO-C Belfast, GRO-C, Northern Ireland. I was born on GRO-C 1945. Before coming to Belfast in 1969, I lived in Sheffield. I studied politics and anthropology at Queen University between 1973 and 1977. Following completion of my studies, I worked as a teacher at Belfast Technical College, now Belfast Metropolitan College, and retired in 2008.

##### **Section 2: How Affected**

2. My son, Russell Davis Edgerton, was born in Sheffield on GRO-C 1966. My daughter, Daniella, was two years old when Russell was born. Russell suffered from a bleed when was a baby and following this was diagnosed with haemophilia. My father had haemophilia and had many blood transfusions throughout his life. He died aged 57, of a cerebral haemorrhage.

3. Initially Russell was treated for haemophilia in the Royal Belfast Hospital for Sick Children (the "Children's Hospital") where he was treated by Professor Bridges. In around 1981, when Russell was 15 years old, he began being treated in the Royal Victoria Hospital in Belfast. I believe it was around this time that he began being treated by Professor Mayne. He remained under the care of the Royal Victoria Hospital for the rest of his life.
4. In 1973, when he was seven years old, Russell suffered from a fall which resulted in a cerebral haemorrhage. He was first treated with a coagulant at the Children's Hospital and after about two days he was discharged. The coagulant would have been some type of blood product, but I do not know which it was, as noted below. Within a day or two of Russell being discharged, I had to take him back to the Children's Hospital because he was slurring his speech and did not seem well. The doctor in casualty, who I did not know, gave me an information sheet which explained what to do in the case of a head injury and told me to take him home. I refused to take him home as I said he was already showing the signs that were indicated on the sheet; namely slurring of his speech and he was a bit dizzy. He was then admitted to hospital. That day he became unconscious and was transferred for treatment at the Royal Victoria Hospital where he had burr holes put in his skull to relieve the pressure. He went into a coma for several days and the doctors thought that he was going to have brain damage. Russell survived the cerebral haemorrhage and it is thought that he was the first haemophiliac in Northern Ireland to survive this type of operation. He did not suffer from brain damage.
5. Initially Russell was treated with Cryoprecipitate when he had a bleed, but when he had the cerebral haemorrhage in 1973 I recall being told that he was being given a new product. I do not recall what it was and I do not recall being told about any risks in relation to this product.
6. When Russell used to suffer from bleeds, he would try to hide these bleeds in order to avoid going into hospital. This only served to

exacerbate the problem and consequently, his bleed would deteriorate necessitating hospitalisation. I remember Russell being given Cryoprecipitate for such bleeds and, in the early 1980s, he received Factor VIII.

7. When Russell was about fifteen years old he moved on to home treatment, and Factor VIII was given. I helped him with his injections which I found quite traumatic. Eventually Russell began treating himself and performing his own injections. He was a very independent person.
8. Russell went to Botanic Primary School and then Suffolk Primary School, both of which are in Belfast, and generally did not have many problems fitting into school as a result of his haemophilia. He did not like people to know that he had it, although he did have to use a wheelchair and crutches when his knees were sore. The secondary school he initially attended was Dunmurry High School and the teachers there did not understand his condition. At one stage his teachers talked to me about sending him to a special school. Russell did not want to attend a special school and asked if he could go to the school at Twinbrook, I spoke to Mr Watson, who at the time was headmaster of a school in Twinbrook, to see if Russell could attend his school. Mr Watson's school was within the Catholic education sector; however, Russell had not been raised Catholic. Mr Watson said that Russell having haemophilia was not a problem and but not being Catholic might be. Nonetheless, the school accepted him. Russell did not like school very much and he left at the age of 15. He was home-schooled for his final year of education. He did not go on to complete any further education and did not get a job. In spite of that Russell had a lot of interests which included natural history, ornithology and geology. He studied astronomy, had a retractor telescope and a collection of blues music and he played the guitar. He had a life that he tried to live to the full.
9. When Russell was around 18 years old, I was asked to take him to a meeting with Dr Mayne. I do not recall exactly when this was, but I know that it was sometime before the local elections, which were held in May



1985. It was at this meeting that Dr Mayne informed Russel and me that he had HIV. As described below, I have recently received Russell's medical records. Although I have not yet had the opportunity to review them in full, I have seen a reference in these records to Russell being tested for HIV on 25 January 1985.

10. After informing him of his infection, Dr Mayne asked Russell if he was gay. I strongly opposed him being asked this question, as I felt it was interference in my son's personal life, particularly in front of his mother. I feel that I reacted more strongly to Dr Mayne's question about my son's sexuality than I did about being told of his HIV diagnosis. My son's preferences were his own business. On reflection, I could only come to the conclusion that Dr Mayne asked if he was gay, to try and find a reason which could have caused his infection with HIV, other than the fact that he had been given contaminated blood products. I was shocked to hear about my son's HIV diagnosis and at first it seemed unreal, though as time went on it became a reality.
11. I also do not remember Russell being given any advice about living with HIV at that meeting. However, Russell was old enough at that time that he may have later received advice without me knowing. We were told that there was no cure.
12. I was not fully aware of how HIV could be transmitted. In 1992 following Russell's diagnosis, GRO-C became very ill. He started to lose weight and we did not know what was wrong with him. I began to worry that he may also have contracted HIV as when Russell did not finish a meal, which was a common occurrence, GRO-C would eat all of the food off his plate. I did not know if HIV could be transmitted in this way. He was tested for HIV at the hospital and he tested negative. It was discovered he in fact had an abscess in his liver.
13. Russell passed away on 1 August 1994 as a result of his infection with HIV. I have described the events in these months before his death below.

### **Section 3: Other Infections**

14. As a result of receiving contaminated blood products, Russell was also diagnosed with Hepatitis. Unfortunately, I do not remember being told which strain of Hepatitis that Russell contracted, however I do know that he was informed of this diagnosis before being told that he had HIV. After a while he was told that he had developed an antibody and that he would be ok. I believe he was about 15 years old at the time.
15. Russell also developed epilepsy around the age of 24 or 25. We were informed that the bleed that he had in his head had caused a scar that was connected with the epilepsy.
16. As set out below, I discovered in 2017 that I was entitled to a payment from the Skipton Fund as a result of Russell being infected with Hepatitis. I did not know what strain of Hepatitis this related to at the time of making the application, but I now understand that this would be in connection with a diagnosis of Hepatitis C.

### **Section 4: Consent**

- 16 Whilst I remember being informed of Russell's diagnosis of HIV, I do not remember being told that he was being tested for HIV. I also do not recall being told that he was being tested for Hepatitis.

### **Section 5: Impact**

17. After learning of his diagnosis with HIV, Russell and I did not discuss it further. He did not want to discuss having haemophilia, so he certainly did not want to discuss having HIV. I think we were in denial about it. His sister, Daniella, has also told me that he did not discuss having HIV with her, although she was aware of his condition. He did not want to face it. Russell just wished to be normal and the HIV diagnosis created a further issue as to why that situation could not be achieved.
18. One of the most difficult challenges resulted from the stigma attached to HIV, particularly due to the stories that were emerging in the media

around that time. By the 1990s there was more evidence emerging in the media about people dying as a result of HIV. This made having conversations about Russell's illness very difficult. That said, I think Russell told his closest friend about having HIV. I have recently spoken to one of his friends who said that he knew that Russell had HIV but they did not talk about it. I am not sure whether or not his friends treated him any differently as a result of his illness.

19. As far as I am aware, he did not have any romantic relationships. I have discussed this with Daniella, who was close to Russell, and she believed that he did not form any such relationships out of fear of transmitting HIV. He had a friend of whom he was very fond. When Russell died she gave me letters that he had written to her, but they were never a couple and she had a partner of her own.
20. His health was relatively good until 1993 when he developed meningitis. Up until that stage he had minor problems with different infections. However, developing meningitis was a much bigger problem and a great worry for both Russell and me. During this time he was treated in the Royal Victoria Hospital in Belfast. He was in hospital for about four weeks. We lived from day to day during this time and he was in terrible pain. I was worried that I was going to lose Russell as a result of meningitis and the doctors did not hold a lot of hope for him either but he recovered. I took some time off work and he returned home to live with me for a period of time before returning to his flat in North Belfast.
21. Despite his physical recovery, contracting meningitis had a heavy psychological impact on Russell. He was terrified that it would return. After his recovery, Russell continued to go out with his friends to bars and would collect glasses in a local pub but he stopped drinking.
22. On 1 March 1994 Russell went to hospital because he did not feel well. Prior to having meningitis, Russell would have avoided going to hospital, but he chose to go because he was frightened of infection after having been so unwell. I remember him having thrush in his mouth at this time which was very painful for him. When he was admitted to hospital on 1



March I was told that he would not live until the end of the year. His condition gradually declined in hospital. At various points we considered bringing him home but we never did. He was on a drip and other forms of treatment and he was afraid to come home.

23. My grandson, my first grandchild, was born when Russell was in hospital. I remember feeling emotional about the baby being born while Russell was so ill. Daniella and I brought the baby to see Russell when he was in hospital. Nobody ever told us whether we should or should not bring him.
24. The greatest impact caused by Russell being given contaminated blood was losing him on 1 August 1994, aged just 27. He died in hospital having developed pneumonia. Not only was my son's life cut short so prematurely, but my family and I also lost a son, brother and uncle. Russell's death was a difficult experience for all of our family. We had not wanted to believe what was happening and our greatest fear became a reality when he passed away. It is impossible to relate the final months of Russell's life, from 1 March until 1 August 1994; it was like living through a nightmare, not being able to do anything to help him.
25. Russell spent the last five months of his life in hospital and when I think about Russell, I always think of the last five months because they were so difficult. When I have dreams about Russell, it is always about him dying. These last five months have clouded my memory of his life and time we spent together. However, going through this process has made me remember the life that he led.

#### *Impact on my daughter*

26. While Russell was in hospital, I was also admitted to hospital as a result of a breakdown. During my stay in hospital, I came to accept that he was going to die, but I do not think my daughter or other members of the family ever did. Daniella only ever saw the good in Russell and I know that she was totally broken after his passing and I believe that this affected her terribly.

### *Impact on my health*

27. During Russell's lifetime I suffered from emotional stress as a result of my son's illness. I first suffered a breakdown in the early 1970s when I was in Tunisia. This happened shortly after Russell's brain haemorrhage. I remember constantly being worried about the worst possible scenario of Russell's haemorrhage. This was exacerbated by the fact my father had died of a brain haemorrhage.
28. I later suffered from a further breakdown in the months before Russell's death. I was admitted to hospital around Easter time in 1994 and remained in hospital for about six weeks. I went back to work in June for a short while before the summer holidays in the months of July and August.

### **Section 6: Treatment/Care/Support**

29. I do not remember receiving much support throughout Russell's HIV illness or treatment. We were more or less left to cope ourselves until Russell developed meningitis in 1993; I think of that time as the beginning of a crisis. The doctors and nurses who treated him in hospital were good to him. I liked Professor Bridges and was appreciative of the care shown by him to Russell when he was younger.
30. I have not received any specific psychological treatment, care or support following Russell's passing. The only psychological care I received was during my hospitalisation a result of my breakdown shortly before he died.

### **Section 7: Financial Assistance**

31. My niece, Julie Knight, is a solicitor and she represented Russell in litigation relating to his infection with HIV in the early 1990s. In May 1991, the government offered to settle the case for £23,500 without the admission of liability (WITN3216002). It is my recollection that Russell accepted the £23,500 payment because he had been advised that he would not live long enough to survive the length of a court case. I think



this advice may have come from The Haemophilia Society but I cannot be sure. Julie has informed me that Russell did not want to continue with the litigation because of his health. He had legal aid and she discussed with him the fact that he could continue with the case but due to the medical evidence at the time it was going to be a long haul. She says that Russell just wanted to get things sorted and did not want to continue with the litigation.

32. In order to receive the payment, Russell had to sign a form waiving any rights to take future legal action. Russell was young and unemployed at the time and I felt that £23,500 was a lot of money to be giving to an unemployed person. As far as I am aware he was not given any advice as to how he could use this money to improve his life. Russell spent the money on a Volkswagen and on motorbikes and spent five weeks camping in France with his friends. He used to attend festivals such as the All-Ireland Fleadh and he bought a hearse to travel and sleep in. He thought it was funny that he travelled in a hearse; it was in keeping with his sense of humour. A prominent singer of that time, Charlie McGettigan, wrote a folk song in Russell in memory of him entitled "*The Old Black Hearse*."
33. In 2017, [GRO-C] attended hospital for a routine blood test at the Royal Victoria Hospital in Belfast. At her appointment, [GRO-C] was told about funding being available for those who have been infected with Hepatitis via the Skipton Fund. I went to see the doctor in the Royal Victoria Hospital to find out more information. At this meeting I was told that Russell's records had been disposed of, but his name was included on a list which showed that he had had Hepatitis. I completed the forms and had to send Russell's death certificate to the Skipton Fund. I received £20,000 and was told that I was one of the last people to receive anything from the fund. If [GRO-C] had not attended for blood tests in 2017, I do not believe that anyone would have contacted me about the Skipton Fund.

## Section 8: Other Issues

34. As set out above, when I went to the hospital following [GRO-C]'s blood test in 2017, I was told that in accordance with hospital procedures Russell's records had been disposed of but a small slip of paper with a list of names on it existed. This slip enabled me to make an application to the Skipton Fund. However, to date I have never been told what strains of Hepatitis Russell had. My former solicitors, Malcomson Law, made a request to the Royal Victoria Hospital on my behalf in an attempt to recover Russell's records. I have since learned that the Royal Victoria Hospital has sent two parcels of Russell's records to Malcomson Law but these have yet to be provided to me; therefore I cannot comment on what they include. After making a request directly to the Royal Victoria Hospital, I have now received a number of packages containing Russell's medical records. However, I have only managed to look at these briefly. In light of this, I do not understand why I was previously told that Russell's records had been disposed of. I have yet to review the records which have been sent to me but I will provide a supplementary statement to the Inquiry should they contain any information which is relevant to the Inquiry.
35. I have always wondered why blood products from America were used to treat haemophiliacs rather than blood products obtained in the United Kingdom. Around the time that [GRO-C] was informed about the Skipton Fund in 2017, there was a suggestion made, I think by Dr Benson at the Haemophilia Centre in the Royal Victoria Hospital when I attended there, that Dr Mayne said that some of the blood products may have originated in Scotland. Dr Benson said that Dr Mayne would be on a television programme about infected blood. We watched the programme but Dr Mayne was not featured. To this day I am still not sure whether Dr Benson meant that the products came from America to Northern Ireland via Scotland, or whether my son's blood products in fact came from donors in Scotland. I have always presumed that American products were used and I believe the rationale behind this was because they were

apparently cheaper than using UK products, or more profitable. I find this rationale for using such products difficult to comprehend.

36. I found attending the Inquiry hearings in Belfast helpful as it was a collective experience. Listening to other people's experience was emotional, but I was sharing that experience and realising I was not on my own in what I went through and what I am still going through.
37. I have never forgotten what happened to Russell but I did not have the stamina to challenge the system, I felt as though it would be a lifetime's work. However now the opportunity has arisen, I want to know what happened.
38. I would like answers to the following questions:
- a. Did my son receive a USA blood product at the time that he was treated for a cerebral haemorrhage in 1973?
  - b. Did the Haemophilia Centre located at the Royal Victoria Hospital in Belfast know, or ought to have known, that the products it used were capable of transmitting viruses?
  - c. At what stage was my son infected with HIV?
  - d. Was there an economic factor in the decision to buy Factor VIII products from the US, as opposed to making it in the UK?
  - e. Have the Cabinet papers revealed relevant details regarding the blood contamination?
  - f. Why was I told that Russell's records no longer exist?

### **Statement of Truth**

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

Signed \_\_\_\_\_ **GRO-C** \_\_\_\_\_

Dated 29-8-2019