Witness Name: Roger Kirman
Statement No: WITN1334001
Exhibits: WITN1334002
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROGER KIRMAN

I, Roger Kirman, will say as follows:-

Section 1. Introduction

1. My name is Roger Kirman and I live at GRO-C, Cheshire GRO-C GRO-C with my wife. I was born on GRO-C 1947. We have two grown up children.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

3. I have severe Haemophilia A with a 1% clotting factor.

4. Originally I received fresh frozen plasma and cryoprecipitate for treating my bleeds and then Factor VIII concentrates. Prior to 1991 these included Factor VIII concentrates from manufacturers Kryobulin, Lister, Profilate, Armour and Monoclate. A copy of the treatment products are attached as Exhibit WITN1334002.

5. I have received treatment from Sheffield, Oxford, Liverpool and Manchester Haemophilia Centres. I went to Treloar College.

6. I am not certain when I became infected with Non A Non B hepatitis later defined as Hepatitis C (HCV) but I believe that it may have been from when I first started using Factor VIII concentrates in the late 1970's due to the changes in the results following the frequent liver function tests I had.

7. My brother George Kirman was infected with HIV and HCV and he died as a result of these infections in 1991. We were never advised nor did we consider that we would be affected by the use of Factor VIII concentrate. We were not told at any stage of the potential risk.

8. I remember that rumours began circulating in the press in the late 1970's about a strange infection associated with the gay community in the USA some of whom were known to be blood donors. Although there may have been discussions within the medical circles we were not told much and kept very much in the dark.

9. I was never told that my frequent liver function tests were indicative of a problem. In the 1980's George and I became aware that the material may carry a real risk of HIV. However I had a fairly demanding job as a TV engineer and I had frequent bleeds so required the Factor VIII treatment. I could not afford to have long stay hospital visits to treat the bleeds alternatively as it would have put my job at risk which in turn would have an affect on my mortgage and would have had an adverse financial affect on my family.

10. I was never informed of the risks when it was believed by the medics that viral infections were contained within blood products. I should have been made aware of this fact because of the potential for infecting my wife, Helen and perhaps passing the infection to unborn children. I was fortunate as Helen and my children have avoided infection but I know many people who have fared much worse.

11. I found out that I had HCV shortly after undergoing a hip replacement in May 1994. I was receiving high levels of Factor VIII ten days post-operatively and a medic decided that it would be a good idea to take advantage of the situation to allow him to do a liver biopsy to confirm if my liver function tests accurately reflected the level of liver damage caused by HCV. It came as a shock to both Helen and me.

12. Shortly after this I was advised that I should take care to avoid my blood or any other body fluids coming into contact with anyone else. I stopped drinking alcohol and was very aware when administering Factor VIII and I very carefully cleaned up after my treatment.

13. I told my dentist of my HCV status for his safety and I made changes to other routines. It affected the whole family.

Section 3. Other Infections

14. I was told that there was a possibility that the concentrates could also carry the prion associated with vCJD. I think there is little point in worrying about this as I understand there is no cure. I am very much of the opinion "what will, be will be".

Section 4. Consent.

15. I believe that it was known there was a problem and that tests were made along with all the usual blood tests associated with haemophilia. However, we were not told that they were looking for something specific.

16. I consented to blood tests but I was unaware that my blood was being tested for HCV or HIV. By this very fact I was provided with inadequate information.

17. To this day I have no knowledge of how the results of my tests were used in terms of research. If I had been advised that the research was necessary then of course I would have consented.

Section 5. Impact

18. I am by nature, optimistic. However, I found the period leading up to the discovery that I was most likely not infected with HIV very stressful.

19. I became Chairman of the local Haemophilia Society Group. I took over this position as the previous chairman and secretary became ill. I watched in disbelief as young colleagues and friends infected by these viruses became ill and died. I have a memory of being on a hospital ward, speaking to a friend who was thin, frail and very unwell. I can see him as he stood next to his drip-stand receiving antibiotics and staring out of the window before we said goodbye. It was the last time I saw him.

20. Although I contracted Hepatitis C and carried it for more than thirty years I have survived the tragedy that befell so many friends and someone with whom I share so many things. My brother George and I were born within two years of each other; he was my elder brother. We both had severe haemophilia and suffered the same pains and joint damage. We both took the same electronics course at Treloar College and shared the same humour. We even shared the same contaminated Factor VIII batches. However, he contracted HIV and HCV and as his CD4 counts fell he developed all the symptoms that come with a failing immune system and he died in 1991 when he was 45. It is hard not to feel that some part of me died with him.

21. George's death was hard for all of us but particularly for his young children who carry the scar of that loss to this day. Equally my wife has lived with the knowledge that she too may be infected with all the implications this will have for the children if we both die.

22. I avoided any discussion of my haemophilia because of the stigma attached and I avoided all discussion of haemophiliacs and HIV. Our family social lives were very much affected and I stopped social drinking altogether. I used to say that my poor walking was caused by accidents.

23. It was an incredibly sad and stressful time which was made more difficult by the media created hysteria. Our wives and family knew or guessed that we were affected, but for their sake and that of our children never spoke of our tragedy outside for fear of ill-informed and unkind comments, or worse.

24. When I became aware of the contaminations through blood products I tried to minimise my risk of infection by reducing the number of times that I used Factor VIII. I saw this as a balancing act to use the material sparingly and limit it to the joints and muscles already affected. The result was that my other joints were inevitably more heavily compromised.

25. I suffered from weariness but it was quite difficult to decide whether this was a result of the HCV or simply caused by the constant pain from my left knee which required replacement.

26. In early 2000 a dual drug treatment (pegylated interferon and ribavirin) became available. Despite the known side effects of this treatment I felt that I had to give it a try. The programme lasted a year during which time I suffered constant flu symptoms and I lost a stone in weight.

27. I remained virus free for approximately 6 months before it returned. I took comfort however in the fact that my liver had a chance during that time to recover due to low viral load.

28. Although I had qualified for this early treatment the area Health Authority initially refused to provide it due to the tremendous cost. I was very angry at this because the HCV came with the haemophilia treatment and I therefore wrote a formal letter of complaint to my MP. After doing this I received a note saying that treatment would be provided but I should realise that its costs would mean that services/treatments would be denied to other patients as a result. I saw this as emotional blackmail.

29. The best treatment at the time was to use pegylated interferon as its effect was to maintain a constant level rather than significant "peaks and troughs". More side effects were associated with "none peg" interferon. As it was I received standard interferon and I suspect cost was the driver of this.

30. My performance at work suffered and I believe I was hard to live with that year.

31. My medical treatment was not affected by my HCV status.

32. It is very hard to judge the full impact that the HCV infection has had on our lives. Haemophilia is such an unpredictable condition that people of my era continually adapt to specific issues as they arise. The changes are very subtle and it is the same with HCV. I suspect that I have adapted to having a restricted social life and I believe it has more of an effect on my wife.

33. We did not tell our two girls that I was infected as they tend to worry about my issues with haemophilia and it seemed unfair to add to their concerns.

34. There were issues around my HCV when my wife and I offered to become foster carers and the support of my haemophilia centre director was required to satisfy the social workers before we could go ahead.

35. In the year 2000 we moved to a larger house and my colleague and I decided to downsize our company and make two small companies with him taking one and me taking the other. This made it possible for me to cope with the HCV issues and to work from home. We had to draw on savings to cope with the change in circumstance.

36. In the early years of my brother's co-infection with HIV and HCV and my HCV status the climate of fear generated by the media was intense. We wanted at the time to campaign and raise funds for the Haemophilia Society and research and we had to do this in fancy dress to obscure our identities; we did not want our families to face potential abuse. I had always been open about haemophilia and had actively taken to the media with George in the past to attempt to make potential employers aware that haemophilia was now controllable and that our "sickness record" was as good as anyone else. However, this all changed with HIV and HCV and we again faced the issue of security of employment.

37. During this time I faced the prospect of redundancy and realised that if I needed to find another job it was unlikely to be easy in that climate and certainly not at the salary I received. The company did offer me another post and we had to move from GRO-C to GRO-C because of it to allow me to commute to the office in Preston

38. It was for this reason that I set up a small company with a colleague to make a living and to support my family.

Section 6. Treatment/Care/Support

39. The relationship with the haemophilia team in GRO-C was generally good and the treatment for haemophilia was better than most. Nonetheless there were failings in terms of the information that should have been provided in the early days. I eventually had to move to the Liverpool Haemophilia centre when we moved to GRO-C.

40. It was not a good centre and as an example I was given a "home treatment" pack of concentrates and discovered only as I got in the car that the material had not been "heat treated" and had in fact been returned from a previous person with haemophilia for that reason.

41. The haemophilia centres were supposed to have Social Workers operating within the centre. I cannot comment on if they were always available or indeed if all centres had them. I have become self reliant in terms of dealing with haemophilia and all the difficulties it brought with it. The issue that came with contaminated products was just one more issue in a list. I have never been one to look too far ahead and have lived for the day with Helen and the kids and did not seek any further support.

Section 7. Financial Assistance

42. At the beginning of 2003 I found out about the Skipton Fund and I was supported by my Haemophilia Centre Director in providing the evidence. I received £20,000 from the fund in October 2004. I cannot recall any difficulties in making the application and I think the only pre-condition to receiving the funds was proof of the fact that I carried the virus.

43. I have not received any other payments.

Section 8. Other Issues

44. I feel that successive governments felt able to avoid responsibility to us because the heart of our community had been destroyed and those of us who survived felt unable to protest loudly for fear of attracting backlash with the stigma attached to both HIV and HCV.

45. I am angry at the injustice of a system in which those responsible for the deaths of so many were never held accountable and of our government paying out the absolute minimum and refusing to accept any responsibility for its part. Some were asked to sign documents preventing seeking justice in the future and successive governments I believe have compounded this injustice by destroying documents and refusing repeated calls to hold a public inquiry until many have died.

46. I know of one particular case and of course there may be others where an older person with haemophilia was infected and became ill with liver failure shortly after infection. There was talk at the time of a liver transplant but it was delayed and eventually the gentleman developed liver cancer from which he died. As he died before any compensation scheme was implemented his widow received nothing.

47. Compensation from the Government of any party (who were determined to accept no blame) was not what I wanted. I wanted legal aid and provision of all records held by the government and haemophilia centres to allow me to pursue the drug companies and government bodies (both US and UK) through the courts for my contamination and the death of my brother George.

48. I recently received a letter from the National Haemophilia Database of the UKHCDO regarding details of forms completed in the 70's and 80's, each time I used a Factor VIII concentrate. I had been informed that all data had previously been provided to me but it does not appear to be the case and not all the paper files have been entered on to the database.

49. These paper files gave the patient name, the date that the product was used, the manufacturer and the batch numbers, the number of haemophilia i/u per vial and the type of the bleed. It is this data which coupled with frequent and dated blood test results would indicate which manufacturer product and batch caused the infection.

50. I was told that it would take some time to retrieve and collate this information before entry on to the database.

51. It is hoped that the Inquiry will receive all the information on the National Haemophilia Database as it is entered. I understand that blood serum taken from certain patients was frozen and stored and that in this way when the test for HIV became available it was possible to test these samples and determine when the individual sero-converted.

Anonymity, disclosure and redaction

52. I do not wish to be anonymous and understand that this statement will be published and disclosed as part of the Inquiry. I am happy to give oral evidence if the Inquiry requires me to do so.

Statement of Truth

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

Signed: GRO-C

Roger Kirman

Dated: 23rd April 2019