Witness Name: A Kirkham
Statement No: WITN1332001
Exhibits: WITN1332002-18
Dated: February 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ALAN KIRKHAM

I, Alan Kirkham, will say as follows:-

Section 1. Introduction

1. My name is Alan Kirkham of GRO-C. My date of birth is GRO-C GRO-C 1947. I am now retired but I used to be a social worker and I also owned and ran a vegan health food shop. Since 2000 I ran my own investment company which I sold in 2015.

2. I was infected with Hepatitis C via my use of contaminated blood products.

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

Section 2. How Infected

4. I have Haemophilia A of moderate severity.

5. I was treated at the Oxford Haemophilia Centre under Dr Charles Rizza and at the Norfolk and Norwich University Hospital under Dr. Hamish Lyall.

6. I received Factor VIII concentrates from the earliest time at which they became available. Prior to this I received Cryoprecipitate. I received treatment relatively infrequently and on demand.

7. At no point was I ever given any warning or advice regarding the risk of infection in relation to Factor VIII concentrates.

8. I know that I was infected with Hepatitis C at the Oxford Haemophilia Centre. I believe that it was in early 1978.

9. I suffered from jaundice in 1978 and at the time I was told that the cause of this was unexplained. However, **Exhibit WITN1332002** is a copy of a letter dated 19th May 1978 from J M Trowell, Lecturer in Medicine to Dr J M Matthews which states "*There is no doubt that he has a serum hepatitis, probably as a result of the cryoprecipitates that he had following a small haematemisis last December. His symptoms started in early April, he noticed that he was jaundiced on the 28th of April…I have discussed the implications of this illness with him, I think that at the present time he is a little bit unrealistic and has failed to appreciate that it may be many months (this was crossed out and handwritten in its place was "weeks") before he is really fit enough to presume (resume) professional duties. However, I have arranged to see him after his liver function tests have been checked next Wednesday and will discuss the problems with him then*". I confirm that I don't remember the medical professionals talking to me about any of this. I also spoke to my ex-wife who I was with at this time and she does not remember any such discussions except for a mention of "*this is strange, it must be an infection or something*".

10. **Exhibit WITN1332003** is a copy of a letter dated 8th June 1978 from J M Trowell to me which states "*You also still have the hepatitis virus in your blood. May I suggest that you have your blood checked again in four weeks time..*".

11. According to **Exhibit WITNXXX004** the date of my first positive test was on 27th March 1992 but I was not told of my infection until 1994. Part of the delay could have been due to me moving house during this period.

12. According to my Norwich Medical Records Hepatitis C antibodies were first detected in February 1994 as evidenced by **Exhibit WITN1332005.**

13. I was told about my Hepatitis C diagnosis by a nurse and not a doctor. I recall that it was a female nurse and she said that it was her job to deal with these things and that she was attached to the Liver Department. She told me that I had got Hepatitis C and that it was not anything to worry about. She said that I may experience flu like symptoms but not to be concerned about this. She gave me absolutely no information in relation to passing the infection on/risks of transmission.

Section 3. Other Infections

14. Exhibit WITN1332006 confirms that I was at risk of vCJD. I only found out by chance about this and it was quite late on but I don't recall exactly when although I had been a vegan for some years when I found out. I was casually talking and laughing with Dr Lyall when vCJD came up in conversation and he said something like "*well actually Alan…..*" and broke the news to me that I had been put at risk of vCJD.

Section 4. Consent

15. I have been tested for various viruses without my knowledge and therefore without my consent.

16. I was unaware that I was tested for Hepatitis C in March 1992.

17. On 22nd May 1978 I was tested for Hepatitis B Antigens without my knowledge and therefore without my consent. The result was recorded as "*Hepatitis B Antigen Detected".* A copy of the pathology report mounting sheet is attached at **Exhibit WITN1332007.**

18. Exhibit WITN1332008 confirms that I was again tested for Hepatitis B Antigens and Antibodies on 27th November 1978; the result of which was negative. This test was carried out without my knowledge and therefore without my consent.

19. Exhibit WITN1332009 is a copy of a letter marked "*Date as postmark*" from C. R. Rizza to me which states "*We have now tested about 300 patients, some only once or twice, some as often as five or six times. We have had "3" test results for you so far and all have been negative".* All of these tests were carried out without my knowledge and therefore without my consent.

20. I have now gone through my medical records (which certainly appear to be an incomplete set) and I can see that I was tested for HIV on at least nine occasions between 1985 and 1992. One of the pathology report cards also has the words "**HTLV III RISK**" stamped in bold and capitalised. These are attached at **Exhibit WITN1332010.** I was not aware that I had ever been tested for HTLVIII/HIV, let alone on a minimum of nine separate occasions. These tests were carried out without my knowledge and therefore without my consent.

21. I was also not aware that some of my medical records had the words "**DANGER OF INFECTION**" stamped on them in bold and capitalised. I attach an example of the same which is dated 2nd February 1990 at **Exhibit WITN1332011**.

22. In conclusion I was definitely tested on numerous occasions without my knowledge and therefore without my consent.

23. I do not believe that I was ever treated without my knowledge but I do believe that I was initially diagnosed with Hepatitis C without my knowledge. There then ensued a delay before medical professionals imparted the news of the diagnosis to me.

Section 5. Impact

24. The mental effects of being infected with Hepatitis C have been wide ranging. When I was first told about my infection I was not at all bothered because I had been led to believe that it would be like having the flu and that I would just work with it. However, when I found out how serious it was I then went through a period of cutting off from my family. I felt that I was somehow toxic to them. My wife and I stopped having sex as I was so worried about transmitting the virus to her and I also sought counselling.

25. In terms of my relationship with my children, I had not realised the effect on them of cutting myself off. It was only when I started talking to my birth children about what had happened to me that I realised how worried they had been in relation to my infection with Hepatitis C. By this time, they were coming up to their early teenage years and I had no idea that they knew so much about Hepatitis C and that they had been talking to their mum about it.

26. I would like to briefly turn *to the emotional effects of haemophilia and* John Bowlby and his theory of attachment. Bowlby suggested that a child would initially form only one primary attachment (monotropy) and that this attachment figure acted as a secure base for exploring the world. The attachment relationship then acts as a prototype for all future social relationships so disrupting it can have severe consequences. A lot of Bowlby's research was carried out on children's wards in hospitals by James Robertson. The breaking of the attachment relationship, by going into hospital, was shown to be seriously damaging for a child. Having met with a lot of other Haemophiliacs I can see the damage which has been caused by the breaking of the attachment relationship as a result of many hospital inpatient stays. This means for many of us of an age never experienced that close bond of Mother and child, grew up with disrupted schooling having to take breaks of up to three weeks every time we had a bleed, returned to school to find friendship groups challenged by these disruptions, unable to play football or rough games in school or Scouts. Many went on to work, where again things became disrupted by bleeds, time away over and over affecting promotion and again friendship groups. For me it has taken a life's work to get over this and therefore you are not looking at a *"nice bunch of happy clappy people".* Rather, we are dealing with a group of people who already come to the table with diverse mental health issues. The one constant in all of this was the long term relationships we formed with the staff at the Haemophilia centre. I have fond memories going back sixty six years of people who cared for me consistently when ever I was in trouble. In fact there were times, as a child, I welcomed a bleed because I knew I would be in hospital where I would be cared for.

27. Therefore, try to imagine the emotional effect of finding out that these people, in whom we had a deep and long term trust, had been the cause of a potentially life destroying blood, and further more we find out, bit by bit, they have lied to us, and in some cases caused this illness when it would appear they could have avoided it. When we are looking at the infection with the various viruses and in my case, Hepatitis C, it must be viewed as a strike on an already damaged stone. Therefore the resultant depression, cutting off and toxicity need to be viewed in such context.

28. As the press began to get hold of information and the scaremongering campaigns began the reality of the seriousness of what I could be facing hit home. I was worried that I had been infected with HIV. I attach the first page a letter I wrote to Dr Matthew on 16th November 1984 at **Exhibit WITN1332012**. I located this letter in my medical records although only the first page. This letter states *"I am a bit worried about all the AIDS* *business particularly as I'm married & I understand that it can be passed on through semen. Would you please give me direct answers to a couple of questions?*

1) *What is the incubation period for aids?*
2) *It is possible for a hemoph. male to give it....."*

29. I attach J M Matthew's response to my letter which is dated 28th November 1984 at **Exhibit WITN1332013** which states "*It seems possible that AIDS is related to infection with a particular varus (virus) called the HTLV3 virus. Many haemophiliacs have an antibody to this virus already. It may be that only some individuals who are especially susceptible to the virus develop the problems of severe immune deficiency described as AIDS....So far, in this country, two haemophiliacs have died with AIDS. The other deaths recently publicised, those of the Australian babies, were probably the result of overwhelming infection from relatively very large doses of infection in blood transfusions donated by an AIDS suffered. The incubation period is possibly about 2 years....Having said this, I hope that it will soon be found that most people react to infection with the virus or viruses involved in the same way as to other infections and become immune. Also, hopefully, before long, vaccination may become possible. Heat treated commercial factor VIII concentrate will be available in the next few weeks which could diminish the risk of infection in those haemophiliacs who have not yet been exposed to infection...".*

30. Turning to the physical effects of Hepatitis C; I have lived with this virus for a very long time and have been extremely lethargic. However, I was none the wiser as to what was causing the lethargy until 1994.

31. Looking back to when I got infected in 1978 I recall being struck down with jaundice which was around the time my second daughter was born. Immediately prior to this time I was running a children's home and was extremely energetic and had a good career in child care. However, being infected with Hepatitis C changed everything for me. I started to get days when I could not get out of bed; a concept which had been totally alien to me before then. I started to struggle at work and had days where I felt unable to do anything. I never really put it down to anything physical at the time and thought that it was more the way I must have been feeling.

32. I underwent a fusion operation of my right ankle for haemophiliac arthropathy in 1976.

33. I suffer with osteoarthritis in my left ankle and I underwent a left ankle arthrodesis on 22nd February 1989.

34. I take codeine phosphate for my ankle pain and despite the fact that both ankdles have been fused, it is the right ankle that plays up more. I have very little movement in either ankle, but enough to make them sore.

35. I also have problems with my left elbow joint.

36. I take NSAID's for my arthritis, medication for a benign prostatic hyperplasia and I use inhalers.

37. I was also diagnosed with Type 2 diabetes, however, I have now lost weight and my bloods are reading normal at present so I am not currently classed as diabetic. However, they are keeping an eye on me.

38. In or around 1991/1992 I underwent a Keller's procedure under Professor Duthie for relief of an arthritic problem in my left big toe.

39. I had to visit the Elizabeth Fry Unit at Norfolk & Norwich Hospital in January 1998 due to severe epiglottitis for which I had a tracheostomy stoma.

40. I have raised Liver Function Tests (LFTs) and I had a biopsy on my liver in July 2000 which recorded "*The appearances are entirely consistent with chronic hepatitis C*" as shown in **Exhibit WITN1332014.** The biopsy was excruciatingly painful and the medical professionals told me to relax and stay still. It was complete agony. If I ever have to endure another biopsy I will be having a general anaesthetic despite the increased risks of the same for haemophiliacs.

41. In August 2012 my Hepatitis C viral RNA came back positive, at significantly high titres. My ALT also shot up to 174. The medical professionals confirmed this indicated that I had active and progressive Hepatitis C infection although I had not developed full blown cirrhosis at this point, things were certainly heading that way. This is evidenced in **Exhibit WITN1332015.**

42. I underwent an ultrasound of 30 January 2014 and the Fibroscan reading was LSM 21.4 (which is referred to in the medical records as markedly elevated), which was suggestive of cirrhosis.

43. **Exhibit WITN1332016** is a copy of a letter dated 12th February 2014 from Dr Aileen Marshall, Consultant Hepatologist to Mr Nicholas Fish, Skipton Fund which states "*a clinical diagnosis of cirrhosis can be made based on the patient's longstanding hepatitis C infection, development of an irregular liver on imaging, splenomegaly and portal hypertensive gastropathy".*

44. I commenced treatment for Hepatitis C on 2nd December 2015 which took place at the Royal Free Hospital. This consisted of an oral regimen of Harvoni (Sofosbuvir/Ledipasvir) and Ribavirin therapy. I suffered with the following side effects which are documented in **Exhibit WITN1332017** which is a letter dated 28th January 2016 which was after completing 8 weeks of the treatment. "*Today, he reports he is physically feeling very drained and tired. He has returned early from a holiday in Portugal due to these symptoms. He reports loss of appetite. He is trying to eat small amounts and has constipated stool…he is currently on 600mg a day of Ribavirin. I am going to reduce this to 400mg once daily, one in the morning, one in the evening. He reports he is using the Ventolin due to his asthma but also due to the shortness of breath on exertion particularly when walking, climbing stairs. Alan also reports that his mood has deteriorated since starting the treatment. He feels that he is much more tearful and also reports insomnia. No mood concerns before starting therapy".*

45. The treatment to cure my Hepatitis C hit me really hard. I was extremely poorly and suffered a period of depression and lost a stone in weight. I did not venture out of the house and it was a very difficult time for me. However, I would have endured anything to be free from Hepatitis C; which was a long term terminal illness. I remember being really depressed because around this time it was my grand daughter's first birthday party and I was really upset as I thought that I would not get to see her start school and get married. I really spiralled downhill in terms of my depression. Thankfully, I managed to complete the full course of treatment and cleared the virus. I was told that my HCV viral load was undetectable which was consistent with a sustained virological response.

46. I believe that I now have sclerosis of the liver, which I understand is an improvement on the suspected clinical diagnosis of cirrhosis. However, I understand that my fibro scan levels are currently normal and my blood test results are also showing as normal which is a really good sign. However, I am monitored regularly in this regard.

47. I was really disappointed with the advice I was given by the medical professionals at the Norfolk and Norwich Hospital in relation to my diabetes. I asked them if there was a link between diabetes and blood levels indicative of Hepatitis C and they said there was not. I did some research and found out that there was a link in that there can be a spike in Hepatitis C readings if someone has diabetes.

48. I therefore moved my diabetes care from the Norfolk and Norwich Hospital to the Royal Free Hospital about six years ago. At the same time I also moved my hepatology care and I have not looked back since. I am so pleased that I moved hospitals and I have nothing but praise and admiration for the medical professionals at the Royal Free Hospital. Conversely, if I am honest, I thought that the advice given by those medical professionals (who I saw) at the Norfolk and Norwich Hospital was useless.

49. Moving to stigma; at first I was very open with people about my infection with Hepatitis C because I did not know that there was any reason not to be. As far as I had been led to believe, it was just like getting the flu. There have been a couple of occasions where I have found out afterwards that people were being cautious around me. One guy stopped playing squash with me but he did not give me a reason for this. About five years later I met him and he admitted to me that he was being silly but was worried that I may have bled on the court. I don't know how many other people have reacted in this way because no one is going to tell you to your face.

50. Turning to my employment, I can confirm that I had the following roles:

1) 1963 – 1968 Various Management Trainee Jobs.
2) Then, the following roles were working with children in care:

1968 – 1972	National Children's Home	House Parent
1972 – 1974	Beds. County Council(CC)	House Master
1947 – 1976	Herts CC	Deputy Superintendent
1976 – 1981	Oxen CC	Head of Home
1981 – 1994	Bridgeways	Therapeutic community I founded for highly disturbed young people

3) 1994 – 1998 The Radical Carrot – a vegan animal rights firm I opened with my partner.

4) The following are all financial advisory firms:
   - 1997 Phillips Mortgages Ltd
   - 1998 Barchester Green Investment
   - 2000 I started "*Investing Ethically Ltd*"
   - 2015 I sold the firm and retired

5) 2015-2018 Classic Occasions of Norfolk – A classic car wedding hire company

51. In terms of the negative effect of Hepatitis C upon my employment I can confirm that I felt this most during the time when I was working in investment. The way I dealt with the ramifications of Hepatitis C, even when it was bad, was to ignore it. This was my way of dealing with everything that was difficult. Up until around 2000 I just tried to ignore any symptoms of exhaustion and in any event, historically I had always put this down to other things and not Hepatitis C.

52. I had worked hard to establish my investment firm but as my health began to fail, I started to become ineffective. I had investment exams coming up and I obsessed about things and my mind was not on work. Initially, when my health started to really plummet which was in or around 2007, I managed to push on and somehow I continued for a further eight years but during this time I began to stop seeing clients and the firm was not bringing in sufficient funds. I basically became a dead weight and it was at this point in 2015 that the kids said "*Come on Alan, let's buy the firm off you".* I was very grateful to them for this.

Section 6. Treatment/Care/Support

53. As far as I am aware, I did not receive any negative or discriminatory behaviour on the part of either medical or dental professionals. I was always very clear with such professionals that I had Hepatitis C. I did experience them putting rubber gloves on but I would certainly expect this and I classed it as sensible.

54. I have never been offered any counselling or psychological support in consequence of my infection.

Section 7. Financial Assistance

55. My view is that I am happy with the support and dealings I have had with the Skipton Fund (SF). I was always treated incredibly well and I would describe the level of support as "*fantastic*". They always kept me updated and I was in regular contact with them.

56. I have never applied for any grants from the SF.

57. I currently receive about £2,000 per month for the EIBSS and I have no problems with the EIBSS.

Section 8. Other Issues

58. I wrote to the Prime Minster on 16 July 2017 and although I have not retained a copy of my letter, I located part of the reply to my letter in my medical records which I attach at **Exhibit WITN1332018.** I draw attention to the following line "*goes some way to reassuring you that the Government is committed to a transparent and fair Inquiry (actually spelt enquiry)*". I certainly hope that this is borne out.

59. I want to know who took decisions that led to me being infected. However, I do not want those people punished. I am not convinced that the people involved before infection acted out of anything but the best as they saw it. However, I do believe that after the infection I was misled and that the people were not open.

60. I know my family and working life have been damaged and whilst I am pleased at the "*support*" money I receive I do think it's time for a significant compensation payment to be made. It is all very well for the Prime Minster to say sorry but what is really needed is an apology backed up with a compensation payment. In relation to the support payments, it is of course notable that they don't come with "*sorry we lied and sorry you got infected*". I believe what I say in this regard is true for a lot of the community although it is fair to say that I am probably less angry about what happened than most.

Anonymity, disclosure and redaction

61. I do not wish to apply for anonymity and I do not want 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........5-3-2020..........