

Witness Name: Robert Ivan Hodgkins

Statement No: WITN0009001

Exhibits: 0

Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROBERT IVAN HODGKINS

I, Robert Ivan Hodgkins will say as follows:-

Section 1. Introduction

1. My name is Robert Ivan Hodgkins. My date of birth is the GRO-C 1968 and I live at GRO-C Berkshire, GRO-C I am currently single and unemployed. My mother, Edna, is now 90 years old and my father passed away in 1998.
2. I was infected with HIV, Hepatitis B, C, and D as a result of being treated with Factor VIII (FVIII) blood products. I am currently on medication to manage my HIV. I have received treatment for Hepatitis B over recent years as it has become available. I have not been given any medication for Hepatitis C or D.
3. In 2018, I applied to the Hammersmith Hospital for all my medical records. These have been sent to me and I believe they are complete. Furthermore, I have obtained records from all other hospitals where I received treatment.

Section 2. How infected

4. Haemophilia runs on my mother's side. I was diagnosed with severe Haemophilia A at 10 months.

5. My parents used to take me to hospital when I was a child and has provided me with information to help prepare this statement. I have 2 sisters, GRO-C

GRO-C

GRO-C my diagnosis came as a shock.

Hammersmith Hospital, London (HH).

6. As a child, my mother took me to HH for treatment. My bleeds used to occur from knocks and these increased when I started school. I would say that my bleeds have remained fairly consistent over the years. I have required treatment on average once per week but on occasions this would increase to 2 or 3 times per week.
7. The consultants responsible for my care at HH were Dr Sampson, Dr Harvey and Dr Morten. Dr Howes was the last consultant who took care of me but I believe this was after I was infected.
8. I also attended the Haemophilia Centre at the Churchill Hospital (Oxford), Guy's and St Thomas' Hospital (London) and St. Thomas's Hospital (London).
9. I believe HH is the one where I contracted all my infections.

Factor VIII (FVIII)

10. From 1969 the doctors treated me with Cryoprecipitate.
11. From 1973 the doctors at HH started to treat me with FVIII concentrate. All parents of haemophiliacs were informed that FVIII were going to revolutionise the way treatment was to be given to treat the condition. My parents put full trust in the doctors and merely accepted the change. They were not told this carried any risk of infection.

12. From about 1976 my local GP treated me with prophylaxis to prevent my bleeds. This carried on until the early 1980s after which I learnt how to treat myself.

13. In the mid-1990's, the doctors started treating me with a genetically engineered product to stop my bleeds.

14. Between 1969 and 2003, my medical notes confirm I had in the region of 3,500 injections.

15. A summary of my treatment is set out below:

a. Dr Craske's Research Work

i. Travenol/ Hyland/Hemofil 1974

b. Hammersmith Hospital

i. Travenol/Hyland/Hemofil 1977, 1978

ii. Cutter (Koate) 1977

iii. BPL FVIII 1977, 1978, 1982, 1983

iv. Armour (Factorate) 1978, 1979, 1980, 1981, 1982, 1983-1986

v. Immuno (Kryobulin) 1982

vi. Alpha (Proliferate) 1986, 1987

c. Poole & General Hospital & Bournemouth Nuffield Hospital

i. Armour (Factorate) 1978

ii. Immuno (Kryobulin) 1979

iii. BPL FVIII 1979, 1981

d. Slough Thames Valley Nuffield Hospital (formerly Wrexham Park)

i. Alpha (Prolifate) 1987

e. Churchill Oxford Haemophilia Centre

i. Alpha (Prolifate) 1987, 1988, 1989

ii. Cutter (Koate) 1988

iii. BPL VIII 1988, 1989, 1990

Hepatitis B

16. In or about 1973/1974 my parents noticed I was unwell. We were away from home, and upon returning home, my father realised that my eyes looked yellow. A GP was called and he said that my symptoms suggested it was likely to be the "hepatitis B", which had already been diagnosed to me.
17. I became aware that I was infected with Hepatitis B when I was in junior school. I cannot recall which doctor told me that I was infected or when I was told. My parents were told that there simply was no treatment available. I note that my previous litigation papers record that I had Hepatitis B in or around July 1974.

Hepatitis C

18. In around 1973 to 1974, my parents took me to HH and asked to meet a consultant to discuss my symptoms. I think it was Dr. Howes who informed my parents I had Hepatitis Non-A Non-B (NANB). She was very angry the infection was caused when I was under her care at the time. My mother believes she referred my case to her superiors to see whether I could get compensation or an acknowledgment but was unsuccessful.
19. I believe it was in or around 1996 that Churchill Hospital tested me. I do not know how I found out about the Hepatitis C; it may have been by letter or by consultation. Before then my parents had only ever been told I was infected with NANB. No one ever previously informed me I was infected with Hepatitis C.
20. My parents were never informed how to manage my Hepatitis C nor were they given any advice. The doctors never even told them that they were testing me for Hepatitis C.
21. My body has since cleared itself of Hepatitis C. I was never treated for it.

HDV (Delta Virus)

22. In 2012 Churchill Hospital diagnosed HDV. I believe the doctors were worried about my liver functions so they carried out extra tests. The tests have confirmed that I am HDV positive.
23. I understand that you cannot get HDV unless you have been infected with or are a carrier of Hepatitis B.

HIV

24. It was about 1984 the doctors told me I was HIV positive. At the time, I was about 15 years old and remember seeing a programme on BBC. This was about raising awareness amongst certain groups of people who were at risk of being infected and included a piece on haemophiliacs.
25. Following this programme, HH was inundated with telephone enquiries from patients. My parents also telephoned and a meeting was arranged with Dr Howes. At the consultation, Dr Howes said that I had been exposed to HIV. My mother who was in the room with me did not understand what that meant. Dr Howes and another doctor attempted to explain that little was known about blood products and HIV and that we should not believe all what we watched on TV. This caused problems with my parents as for a year they did not realise that I was infected. I understood that I had it, but did not understand what it meant. Nonetheless, due to our concerns, she arranged for tests to be carried out in May 1984. These test results confirmed that I was HIV positive.
26. The doctors did not tell us much. I do not know whether this was because they did not know themselves or whether they only told us what they wanted us to know. I was very young and became very worried partly because the doctors failed to tell me much.
27. I began to have regular consultations with doctors. The doctors informed me about the risk of passing the virus on sexually and that I should be careful. They attempted to reassure me by saying that I should not worry about the

way the media was portraying HIV. It was accepted that I was a risk to others but that risk was not as great as had been portrayed.

28. I do not consider the information the doctors gave was adequate.

29. I believe the doctors should have told me about what they knew much sooner than they did. In 1983, there is a letter in my medical file from the Department of Health to my GP stating that I was HIV positive. I have no reason to believe the contents of that letter is not correct and for that reason the doctors should have told my parents then. If it was not for that TV programme, perhaps we would not have got to know about my infection.

30. The doctors told me that there was no treatment available for HIV. They only said that my medical condition would be monitored.

31. Around mid 1990s my immune system weakened significantly but I was not being observed by a consultant for my HIV. I was however a member of a support group who were able to provide me with information about my symptoms. Through a newsletter provided by the support group, I was informed of a Garden Clinic in Slough. I decided that I would be better cared for by them as Churchill Hospital had let my immune system become dangerously low and they had not put me on medication for pneumocystis pneumonia. I remained with this clinic until 2014. I believe that the guidance and support given to me by the Garden Clinic helped to save my life.

Section 3. Other Infections

32. I received a letter from Churchill Hospital which stated that I had been treated with blood of a person who had died of CJD and that I was at risk. That was in the early 1990s. Since then I have not heard anything further.

Section 4. Consent

33. The doctors at HH never asked my parents for permission to treat me with FVIII products. If they had explained the potential risks, they would not have given their consent.

- (a) Hepatitis B – I believe the doctors carried out tests to see whether I was infected. These tests were done without my knowledge or consent; however my parents were aware of these tests. The doctors did not treat me for this as they had informed me that no treatment was available at the time in the early 1970s.
- (b) Hepatitis C – I believe the doctors tested me for Hepatitis C and that this was with my knowledge. They told me that I was free from Hepatitis C but had antibodies in my blood and had therefore been exposed.
- (c) HIV - The doctors are treating me for HIV and this is with my knowledge and consent. They tested me for HIV with my knowledge and consent but I am not sure whether there were early tests which I did not consent to.
- (d) Hepatitis D – I found out in approximately the late 2000's whilst under the care of Churchill Hospital. At the time I was under Dr Jane Collier. I was told that this was non-treatable and that it was a progressive type of hepatitis. Thereafter I had liver biopsies.
- (e) Research – I volunteered to take experimental antiretroviral treatment. I have taken different types of treatment, which I believe helped me to manage my HIV. This has been with my knowledge and consent.

Section 5. Impact

Education

34. My infections had not affected me at junior school, but they certainly affected my secondary school education.

35. I was around 15 years old when I found out I was HIV positive. This affected my education because I was left to wonder whether or not I was going to die. The doctors did not help me because they told me very little. I missed a lot of school time because I had to attend hospital appointments. When I was at school, my concentration was poor because of my low mood and depression.

After leaving school

36. From the age of 16 to 21 I had not been in education, and I was also not able to work. I then tried various things; I went to college and did education courses, but I was badly affected by my conditions and therefore could not perform as well as I would have liked.
37. At that time my life was very bleak. I was unemployed and had no direction in life. I felt unable to speak with anyone about my HIV because I did not know how they would react. I was not offered any counselling or any other form of help. This is time when I really needed support and guidance but there was no one there to help me.
38. I was interested in doing creative work. I did training in creative fields such as film making and writing and had opportunities, provided to me from a relative, however I was unable to grasp them due to my situation. My ambition was never likely to be fulfilled because of my poor mental state.
39. I did some training for film-making. I also went back to college; however, I never finished my course due to my health deteriorating.
40. I spoke to doctors to get more information from them. As I got older, I began to make my own observations and realised that all what had been reported in the media was not true. I had an interest in science and knew a fair deal about my conditions, but nothing that would make me think that I would not die from HIV. At the very least, I knew that I would not die immediately.
41. I knew that I was not able to do just any kind of job, so I had to be very careful as to which path I chose for myself. My plan then was to get a certain level of training, but it did not go very well.
42. As a result of my poor health, and never being able to engage in a long-term employment, I have struggled financially and I have never had the opportunity to build a career for myself or to find my niche.

43. I was advised by the hospital to apply for disability support. This gave me some financial stability.
44. As a result of my financial situation I was not able to get a mortgage and had to continue to live with my mother.
45. I have managed to get into paid employment for short periods of time but because I was constantly on medication my ability to work was restricted and I felt trapped.
46. It was a bleak time for me, as I struggled with my infections and I never felt like I could be completely open and transparent with other people. I was afraid of other people's reaction. The only people who knew about them were my parents, both of my sisters. I did have friends who were aware of my condition and it difficult for me to join in with them.
47. In the early 1990s the doctors had realised that my immune system had become very weak. At that point I had to deal with not only the mental effects of my illnesses but also the physical effects.
48. Since there was no one specific treatment for HIV, agreeing to the experimental treatments seemed like my only chance. I did not necessarily believe that those drugs would save me, but I hoped that they would save someone else in the future.
49. As a result of the various experimental HIV treatments, I have developed serious long-term side-effects. These include: problems with my kidneys and my blood lipids (which affects my metabolism) and damage to my central nervous system. As a result of the latter I had to have a brain scan because the doctors were worried about the brain damage.
50. The medications have been also a massive strain on my liver (together with the Hepatitis B and D) and I had to have my gallbladder removed in 2016.

51. I have also struggled with severe fatigue and depression. A drug called Sustiva caused me to suffer from psychotic episodes. It made me delusional and even more depressed.
52. The medications also affected my bone density, caused my arthrosis and osteoporosis.
53. Having to be dependant on drugs makes me feel vulnerable and I am truly unhappy having to rely on them.
54. My illnesses still prove to be a challenge for me in a social sense. It had been difficult to form any long-term relationships. I live with my mother, and this is how I keep in touch with my sisters, as they sometimes visit us.
55. My father passed away in October 1998. I recall that when he first found out about my infections, he was extremely angry and disappointed with NHS. The government was meant to put £7 million aside to make us self-sufficient in the supply of Factor VIII; yet instead they continued to import contaminated Factor VIII from America.
56. I was and still am disappointed with NHS for knowing that the blood products were not safe to use and deciding to treat people with them.
57. Regardless of the fact that my conditions are much more stable now, I am still worried about my future, as HDV is a very severe and progressive form of Hepatitis, so I do not know what to expect from it in the future.
58. My illnesses also affected my mother. She cared for me due to my Haemophilia; my infections put her at risk as she often had direct contact with my blood.
59. Many years ago, I recall one instance in HH, whereby my mother went with me to the hospital and two nurses came in to attend me, wearing masks. They made a statement about that they were shocked as to how my mother was able to manage my Hepatitis at home.

60. I also recall that my mother had to have a Hepatitis B injection, to protect her from contracting it from me.

Section 6. Treatment/Care/Support

61. I do not recall having any difficulties in accessing my treatment. I believe that I was given anything that was available at the time.

62. Originally, I was not offered any counselling in relation to my infections or the treatment. I think that it would be very helpful, as I have truly struggled.

63. I have recently been seen by a psychologist and I do find it to be of a great help. I have been seeking help of psychologist for the past three or four years.

Section 7. Financial Assistance

64. I received £20,500 from the MacFarlane Trust in 1991 as part of the benefit programme set up by the UK Government for haemophiliacs infected with HIV as a result of the Contaminated Blood Scandal. I had to sign a waiver in order to receive this payment.

65. I also received monthly payments and a winter fuel payment.

66. Since about 2010, I have also received regular annual payments of around £11,000. Those payments did increase; however, I am not sure by how much.

67. Overall, the MacFarlane Trust has not been very helpful to me. They never provided me with any assistance for house improvements as I did not own my own home. The home I lived in was owned outright by my mother. I felt that I was discriminated against. Since I was unable to obtain a mortgage, I could not possibly own my own home.

68. I was also involved in the American litigation against the drug manufacturers.

69. I have not received any payments from The Skipton Fund because I have naturally cleared it. The main issue that I have encountered with the Skipton

69. I have not received any payments from The Skipton Fund because I have naturally cleared it. The main issue that I have encountered with the Skipton Fund is that they are not willing to acknowledge my HDV. As a result of this, I have not received any financial assistance from them for that infection. I believe that this is very unfair, as HDV is a serious and progressive infection.

Section 8. Other Issues

70. I feel terribly let down by the health system. I cannot comprehend how this could be allowed.

71. The viruses I have been infected with affected my life tremendously. If it was not for them I am certain that my life would have been completely different, and I would have a much better quality of life.

Anonymity

I NOT RELEVANT am prepared to give oral evidence in the Public Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 15-3-2019