Witness Name: R J Warwick
Statement No: WITN1592049
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INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF RICHARD JOHN WARWICK

I, Richard John Warwick, will say as follows: -

Introduction and Early Life

1. My full name is Richard John Warwick, my date of birth is GRO-C 1965. I was born in Scarborough, North Yorkshire.

2. I make this second written statement in response a request under Rule 9 of the Inquiry Rules 2006 dated 13 June 2019.

3. I was born with severe Haemophilia A (<1% Factor VIII).

4. In my early years, my parents were very anxious at the number of swellings and bruises they were seeing on me as a toddler. Predictably, local social services got involved - a terrible time for my parents. X-rays, ice packs and plaster casts were the 'norm' when ever I was taken to my local hospital in Scarborough. Infections were always assumed, usually followed by aspirated joints, and drains. I was diagnosed with Haemophilia at the age of 2 Years and 9 months following a referred visit in 1970 to Hull Royal Infirmary because of a large, painful swelling to my right hand, and it was in Hull where I was first treated with Cryoprecipitate. Hull Infirmary was furious with Scarborough Hospital for not testing and diagnosing me sooner. However, the doctors at Scarborough Hospital had no idea how to administer it, and it was several weeks before they were able to treat me for bleeding episodes. This often involved using cannulas rather than IV needles for infusion.

5. On one particular occasion, I was restrained by nursing staff in a side room of the children's ward. My left leg was locked bent and my knee severely swollen (a joint bleed). The ward sister, a burley woman, sat on my leg in an attempt to straighten it. I screamed and screamed. I will never forget that day.

6. I spent much of my first eight years of life in an out of hospital in plaster casts, traction

and calipers. My parents were very protective of me, fearing further bleeding episodes. While at home, my parents limited my movements. I was not allowed to go outside or interact with other children. I had no formal education whatsoever and was unable to attend a mainstream school.

7. In 1973, due to an intervention from the local education authority, I started to receive home tuition three times a week from a retired teacher.

8. It was in early 1974 that my parents heard about a specialist boarding school in Alton, Hampshire that had facilities to care for children with Haemophilia.The consensus was that I should attend the school when I reached ten years of age.

How infected

9. I was infected with HIV, Hepatitis B and Hepatitis C as a result of receiving contaminated Factor VIII blood products used to treat my haemophilia.

10. In July 1975, I was referred to Dr Layinka Swinburne, a Haemotologist at St. James's University Hospital, Leeds. From September 1975, I was prescribed home treatment. This is when I was first given the commercial freeze-dried Factor VIII product 'Kryobulin'. This was sent from Leeds Hospital to the pathology laboratory at Scarborough General Hospital. My father collected it from the hospital when needed and brought it home to use. I soon became competent at mixing and administering my own treatment under supervision.

Treloar College

Hepatitis B

11. Just prior to attending Treloar College, in a letter dated August 1976, Dr Peter Kirk, a haematologist at the school, assured Dr Swinburne that 'I would be restricted to Kryobulin while I was at college' in a response to her concerns. She had previously mentioned the prevalence of 'Australia disease' in a letter to a haemotologist at the college, the now unused term for the surface antigen of the Hepatitis B virus (Australia antigen).

12. In September 1976, I started school at Treloar College. Been so far away from home, I was incredibly homesick for several weeks. The haemotologists at the College were Dr Peter Kirk, Dr Anthony Aronstam and Dr M Wassef.

13. Initially there were no treatment facilities at the Upper School and I remember going to Treloar Hospital for treatment with cryoprecipitate on two or three occasions.

14. In either late 1977 or early 1978, we were queueing for the dining hall as was the normal procedure for school meals. On at least two occasions when entering the hall, all the haemophiliac boys were segregated from the other children and seated at long refectory

tables. The tables had organised place settings. All of the blue plastic plates were marked with small red labels, as were the stainless steel serving dishes. We were all confused and very worried. We were served separately from the other pupils and the food was also removed separately by the same staff member.

15. Hepatitis B test : 18th January 1979. The test results showed that I was antibody positive (anti-HBs), verifying that I had contracted the virus, then subsequently developed immunity to any future infection. I was never told of the diagnosis.

16. It is normal practice to check the inhibitor status of haemophiliacs once or twice a year, but between 1976 and 1979 very frequent blood samples were taken from me. Every four weeks was commonplace, but in one instance, I was tested every two weeks. These I have now discovered, were liver enzyme tests : S.G.O.T (AST) / Alkaline Phosphate / Bilirubin etc.

Possible source of early HTLV-3 infection

17. From my treatment records, I have identified from 1978, multiple doses of HTLV-3 infected Armour 'Factorate' commercial blood products that were given to me at Treloar College, with their corresponding batch numbers and infusion dates. I received many different brands of Factor VIII concentrate during the six years I attended the college, despite the resident haemotologist assuring that I would only ever receive 'Kryobulin' during the time I was there. This was certainly not adhered to. I was never told that there was any difference between the products, nor was I told of their origin, or any possible risks associated with them.

18. I do not know how Treloars were able to keep detailed records of the batch numbers etc that I was treated with as it was common for the labels from the bottles of treatment to come off during preparation. They were put in water to warm them up and then put in the mixing machines and it was in the mixing machines that labels regularly came off.

HIV and outbreak of suspected 'Glandular Fever'

19. In July 1981, many haemophiliacs simultaneously suffered from an outbreak of what was thought to be Glandular Fever. Two 'Paul Bunnel' tests were performed without my consent. The results of these tests both tested negative for the Epstein Barr virus. None of the boys at Treloars were sexually permissive and kissing was strictly forbidden at the school. There is medical literature linking Glandular Fever type symptoms / swollen lymph glands etc. to early aggressive HIV infection.

HIV and Seizures / Epilepsy

20. I started to have seizures in late summer 1981, and was subsequently diagnosed with Grand-Mal epilepsy. There is no history of epilepsy in my family. Seizures are a relevant neurological symptom of aggressive HIV infection. This is due to the fact that the HIV virus breaches the blood-brain barrier. I was prescribed anticonvulsant medication which was only partially effective at controlling them. Unfortunately, the medication I was given

(Phenytoin), caused severe gum overgrowth, bleeding, and dental problems. Several teeth had to be extracted during the time I was taking the drug.

21. I continued to have fits and accidents over the course of many years, resulting in numerous trips to A&E following serious injuries. In August of 2000, my anticonvulsant treatment was eventually changed to Sodium Valproate, which I still take to this day.

HIV diagnosis

22. My UKHCDO records show I was diagnosed with the HIV (HTLV-3) virus on 27 December 1984. However, it wasn't until some years later that I was officially informed of my HIV status. I was told I was HIV positive by my then GP Dr James Adamson in 1988, during a routine check-up regarding my continuing epileptic seizures. The news hit me like a train. I was in disbelief, confused and very frightened. I vividly remember the walk home to tell Tina.

Hepatitis C / non-A non-B diagnosis

23. I was clinically tested and diagnosed with non-A non-B Hepatitis in February 1991 by my haemotologist in Leeds, Dr McVerry, but he never informed me. There is a very good possibility that I was infected long before this, but I have been unable to find any specific mentions, other than virology tests result.

24. A further test was performed by consultant microbiologist, Dr Derek Johnstone at Scarborough Hospital in May 1993 and he sent a letter to my new GP, Dr Lynne Grove in April 1993 with the results. I have no clear recollection of when I was told about my Hepatitis C infection. The first serious mention of Hepatitis C was made a few months before I started treatment in 2003.

Other infections / notifications

vCJD

25. I was sent a letters in October 2004 and March / July 2009 stating I may have been exposed to and/or infected with vCJD as a result of being given infected blood products and was 'at risk' from a particular batch which doctors had identified as possibly being contaminated with vCJD.

Consent

26. Based on my medical records, I was tested without my knowledge and without my consent on a great many occasions, especially at Treloar College. I was never informed that I was being tested Hepatitis B, C or HIV when blood samples were taken from me.

Impact of the viruses

27. The psychological effects of being infected with HIV and Hepatitis C predominantly revolve around the stigma which is attached to the infections. The stigma surrounding HIV / AIDS, which was created in large part by the media in the early 1980's, was that is was dirty and transmitted as a result of immorality. As a result, I have suffered from severe depression and anxiety. I also carry a very heavy feeling of guilt that I am still alive, as so many of my haemophiliac friends have passed away. I am one of the few haemophiliac boys from Treloar College that has survived into adulthood.

28. The physical effects of being infected is that I am always tired and lethargic. I have always looked very gaunt. I suffer from nausea and diarrhea as a result of the HIV medication that I will now have to take for the remainder of my life.

29. The impact of being infected with HIV, Hepatitis C has had a profound effect on not only myself, but that of both of our families. My mother and father have had to go through hell throughout my life and I cannot find words to express how truly grateful I am to them for their loving support over the years.

30. My wife has always been very loving towards me and incredibly supportive. Her immediate family were initially and understandably concerned, but have always been extremely supportive and understanding.

31. In the spring of 1990, my fiancé became pregnant. This was an unplanned accident - we had always been extremely careful. During a consultation, it was explained to us in very strong terms that it would be best for my fiancé not go through with the pregnancy, as there was a probability that the child could be born HIV positive. The mortality rate of HIV positive adults was exceptionally high, and I had been very lucky to date, but was living on borrowed time. There was absolutely no treatment available for HIV at the time, nor was there any access to 'sperm washing' / IVF as there is today. Tina was very worried that she had also been infected with HIV. We were both totally heartbroken.

32. My sister and her husband decided not to have any children when they got married. Although I cannot definitively prove it, I feel this may have something to do with the fact that we have been unable to have children of our own and her empathy for our situation.

33. After we got married in 1991, we decided to purchase a small bungalow in a quiet rural area well out of town, so that we would not have to face the problems that could arise if a whole neighbourhood became aware of my infection status. We had to scrimp and scrape to find enough money for the large down payment.

HIV treatment and side-effects

34. The years from 1981 to 1987 were the worst. I was not being treated for my HIV but was having fits.

35. The first treatment I received for the HIV infection was AZT (Zidovudine) in March 1991. I remained on this antiretroviral medication for approximately six years, finishing in

January 1997. I was initially placed on a very high dose of 1000mg a day. The side-effects of AZT were dreadful. It caused nausea, weakness, vomiting and dizziness to name but a few.

36. I was also prescribed Septrin / Trimoxazole long-term, to treat outbreaks of oral thrush and help prevent me from developing opportunist infections.

37. From early 1997, other drugs options were tried for the treatment of my HIV infection. Some caused problems and were promptly terminated. One such drug, DDI (Dididosine) for about 6 weeks caused both of my feet and lower legs to swell. In the ensuing years, I went on to developed resistance to many antiretroviral drugs, before a four drug combination HAART therapy was found, which to date has kept my viral load under control. Even this newer HIV medication combination therapy causes a loss of appetite and sickness, so I take daily nutritional supplements to compensate for my low food intake.

Hepatitis C treatment and side-effects

38. The first course of treatment I received for Hepatitis C infection started on 4 November 2003. This comprised of Pegylated Interferon and Ribavirin. I remained on the course for three months until the end of February 2004. The treatment had no effect on the Hepatitis C infection. I was told that my viral load had not dropped at all.

39. The second course of treatment I received for Hepatitis C infection started on 5 June 2013. This comprised Pegylated Interferon, Ribavirin and Telaprevir. I remained on this course until 16 July 2013. This course of treatment also failed to reduce my viral load and was terminated prematurely to prevent resistance to future treatments.

40. A liver stiffness test (fibroscan) performed in December 2014 returned a score of 24.8 Kpa's, Advanced cirrhosis was identified in my hepatology notes.

41. The third and final course of treatment I received for Hepatitis C infection was started on 27 August 2015 and ended on 19 November 2015. This short twelve week course comprised of Harvoni (Sofosbuvir / Ledipasvir) Ribavirin. Following treatment, I have now 'cleared' the virus.

42. The side effects the first course of Interferon and Ribavirin were severe and frightening. My entire body would be covered in a rash. Psychologically, the drug treatments made me angry and irritable. I became a different person. I would frequently argue with my wife and got very frustrated. The rashes and swellings caused extreme itching and pain and made me want to tear my skin off. These affects were mirrored during the second course of Hepatitis C treatment, only worse with the addition of the drug Teleprevir. I did not have any appreciable side effects to the third and final course of Hepatitis C treatment when taking the drug, Harvoni.

43. My UKHDO records state that I am still having follow up every 6 months in respect of my

Hepatitis C. This is not the case. Following my third course of treatment I had 2 tests; one after 6 months and one after a year. I was discharged after the second of these tests and have had no follow up or monitoring since.

Education and Work

44. Upon leaving Treloar College in July 1982 after taking my final exams, I attended Scarborough Technical College for courses in both in computer sciences and a HND in electrical engineering and electronics particularly as it was something I could do sat down.

45. Despite having qualifications, my infected status has hindered me greatly with regards to a future career. I wanted to become an electronics and software engineer - particularly, programming. However, due to the infections of HIV and Hepatitis C, ongoing seizures, severe haemophilia and associated joint problems, combined with the medication I have to take with all their side-effects, I have been unable to commit to even doing part-time work. Due to seizures, I have never been able to drive, which has severely limited my independence, especially now as I become less mobile.

46. As I am unable to work, the financial effects have weighed heavily on me as I am cannot provide for my wife as I would have wanted. It would have been wonderful to purchase a suitable property that could be adapted to accommodate my disabilities and needs. Tina is only able to work on a part-time basis, as she has to spend a great deal of her time looking after me.

Insurance

47. I have also never been able to take out life insurance, which is very distressing, as I would have liked to have had the assurance that my wife will have security and be properly looked after when I am gone.

Care and Support

48. I am aware that different forms of limited counseling have been made available to victims through the various trusts over the years, however it is not something I have ever considered or wanted to participate in.

49. I greatly miss the Macfarlane Trust weekend breaks that they organised every two years or so. HIV infected haemophiliacs could meet up and enjoy respite care together. Other events allowed partners to attend along with us.

50. A treatment which I have always found impossible to obtain, is hydrotherapy. Hydrotherapy would help enormously in helping to strengthen muscles to prevent further

joint damage and increase my mobility. Unfortunately, hydrotherapy is only available through private healthcare and I am unable to afford the high costs involved. The EIBSS does not provide such support, nor did the Macfarlane Trust or Skipton Fund when they were in operation. It was provided at Treloars.

Financial Assistance / Grants and Trusts

Hepatitis C / HIV

51. I signed waiver in 1991 as par to the HIV litigation settlement. We were in Sheffield and we were all told if we didn't sign the waiver none of us would get anything for HIV.

52. I was Hepatitis C positive in 1991 but Dr McVerry never informed me. I was not made aware of my Hepatitis C status until much later.

53. I received two lump sum payments in relation to my Hepatitis C. The first payment was the Stage 1 Skipton Fund payment of £20,000 which I received in 2001. I then had the Stage 2 payment of £25,000 because I had developed liver cirrhosis. I now receive £1,100 monthly. I also get a similar level of EIBSS support for my long-standing HIV infection. I believe MFT payments originally started at £150 per month.

The Macfarlane Trust / Skipton Fund

54. The process of applying for a grant from the support trusts is extremely difficult. There are so many hoops to jump through to make a claim. The application forms are long and complex. The information which is required is means tested, intrusive, demoralising and monotonous.

55. The first and only application I made to the Macfarlane Trust, was for help with the cost of replacement car, as our old one had holes in the floor - the claim was flatly refused. Only asked for second hand car. Told had to go through Motability.

56. I experienced particular difficulties when I applied to the Skipton Fund to have the windows in my house double-glazed. The whole process was very demeaning. I was refused twice only to be accepted on the third application. I had to find the three lowest possible quotes and even then, I was still required to pay a substantial amount towards the cost of the windows from my own savings, as the Skipton Fund refused to pay the full amount. When finished, the work was of poor quality and the double-glazing firm went into liquidation. We had to have it put right by someone else which we then had to pay for.

Other Medical Issues

57. I have suffered from severe Peripheral Neuropathy in my lower legs and hands since

starting on HAART antiretroviral treatment for my HIV infection. It is incredibly painful and I can suffer episodes at any time - especially at night.

58. I experience ongoing problems with my long and short-term memory and concentration. I cannot recall important dates and events that have occurred during my lifetime.

59. Whenever I get run down and depressed, I can get outbreaks of oral thrush. This was a major and distressing problem pre HIV treatment, when it would be impossible to eat, due to the inside of my mouth and throat been lined with a carpet of spots and lesions. I would be given liquid food supplements.

UKHCDO Records

60. I was originally provided with my UKHCDO records in October 2018. I was then written to again on 10 June 2019. A copy of that letter and my updated UKHDCO records is exhibited at **WITN1592003.** It is clear from this letter that the UKHDCO records have not been accurately kept.

61. Furthermore, there is a gap in my UKHDCO records from 1983 to 1986. I believe I had treatment during this period. When I raised this with St. James's University Hospital in Leeds I was told that the records relating to my treatment in this period had been lost in a flood.

Anonymity, disclosure and redaction

62. I do not wish to apply for anonymity.

Statement of Truth

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

Signed GRO-C

Dated 19/06/19