

Witness Name: R J Warwick
Statement No: WITN1592001

Exhibits: 0

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RICHARD JOHN WARWICK

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

Section 1: Introduction

1. My full name is Richard John Warwick, my date of birth is GRO-C 1965.
I was born in Scarborough, North Yorkshire.
2. My current address is GRO-C
GRO-C North Yorkshire, GRO-C I am married to Tina Mary Warwick. We got married in June 1991 and have no children.
3. I have severe haemophilia A. I was diagnosed at the late age of three years old following tests at Hull Royal Infirmary. Prior to diagnosis, I spent much of my early life in Scarborough Hospital in plaster casts, traction and block splints. Despite the diagnosis, it was still several months before I was treated for my haemophilia. The doctors at Scarborough Hospital did not know how to administer the Cryoprecipitate that I had been prescribed.
4. I was treated with Cryoprecipitate in Hospital when ever I had bleeding episodes. I always had severe anaphylactic reactions to the Cryoprecipitate. These reactions had to be treated with injections of the antihistamine, Piriton.

Section 2: How infected

5. I was infected with HIV, Hepatitis B and Hepatitis C as a result of receiving contaminated Factor VIII treatment used to treat my haemophilia.
6. At the age of 9 in July 1975, I was referred to Dr Layinka Swinburne, a Haematologist at St. James's University Hospital, Leeds. From September 1975, I was put on home treatment. This is when I was first prescribed the commercial freeze-dried Factor VIII 'Kryobulin'. This was provided by Leeds Hospital and delivered to the pathology laboratory at Scarborough General Hospital. My father collected it from the hospital and brought it home to use. I soon became competent at mixing and administering my own treatment.
7. In September 1976, I was sent to the disabled children's boarding school, Lord Mayor Treloar College in Alton, Hampshire where I received education and on-site haemophilia care until I left in July 1982. The haematologists at Treloar College were Dr Peter Kirk, Dr Anthony Aronstam and Dr M Wassef.
8. I was first tested for the Hepatitis B virus in 1977 whilst at Treloar College. Several weeks prior to being tested, I remember been taken ill along with a number of other haemophiliac boys at the same time. The test revealed that I was antibody positive (anti-HBs), verifying that I had contracted the virus, then subsequently developed immunity to any future infection.
9. I was given multiple doses of HTLV-3 infected Armour 'Factorate' commercial blood products while I was at Treloar College. I have the implicated batch numbers and the corresponding dates I was given the infected batches. I was given many different brands of Factor concentrate during the six years I attended Treloar College.
10. During my time at Treloar College, many haemophiliacs simultaneously suffered from an outbreak of what was thought to be Glandular Fever. Two 'Paul Bunnell' tests were performed without my consent. The results both

tested negative. It is now widely accepted that Glandular Fever type symptoms indicate early HIV seroconversion / infection.

11. Upon leaving Treloar College in July 1982, I was put under the care of haematologist Dr Bernard A McVerry at the Haemophilia Centre at St. James's University Hospital, Leeds. I continued to receive non heat-treated commercially sourced Factor concentrate blood products for many years.
12. I am currently under the care of haematologist Dr Martin Howard, at the Haemophilia Centre at York District Hospital.
13. In 1981 at the age of 15, I started to have seizures. I was diagnosed with Grand-Mal epilepsy. There is no history of epilepsy in my family. Epileptic seizures are a relevant neurological symptom of aggressive HIV infection. I was prescribed anticonvulsant medication which was only partially effective at controlling seizures. Unfortunately, this medication (Phenytoin) caused gum and dental problems. I had to have several teeth removed during the time I was taking it. I had many fits and accidents, resulting in trips to A&E due to serious injuries. In August of 2000 my anticonvulsant treatment was changed to Sodium Valproate which I still take to this day.
14. My medical records show I was diagnosed with the HIV (HTLV-3) virus on 27 November 1985. However, it was not until three years later that I was informed of my HIV status.
15. I was told I was HTLV-3 (HIV) positive by my then GP Dr James Adamson in November of 1988.
16. In the spring of 1989, my fiancé Tina became pregnant. This was an unplanned accident. It was explained to us in very strong terms that it would be best for Tina to abort her unborn child, as there was a high probability that the child could be born HIV positive. The mortality rate of HIV positive adults was very high and I had been lucky to date, but was living on borrowed time. I was expected to live for up to two years following infection. There was absolutely no treatment available for HIV at the time. Tina was very worried that she had also been infected with HIV. We were both heartbroken.

17. I was not given adequate information to help me understand and manage the infection. I should have been informed in 1985 that I had been infected with HIV as a result of receiving infected blood products - not three years later.

18. In addition, adequate information should have been provided to help me understand the nature of the infection and what I could do to manage it. The information that was given to me regarding the risks of transmitting the infection was vague to say the least.

19. I was officially diagnosed with Hepatitis C (non-A non-B Hepatitis) in March 1993. The test was performed by consultant microbiologist, Dr Derek Johnstone at Scarborough Hospital. I was informed of my Hepatitis C infection by my new GP, Dr Lynne Grove in April 1993.

Section 3: Other infections

20. I was sent a letter in October 2004 and March / July 2009 stating I may have been 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.

Section 4: Consent

21. I was tested without my knowledge and without my consent on many occasions. I was never informed that I was being tested for HIV, Hepatitis B or C when blood samples were taken from me. I know now that some of these tests were done for research purposes, specifically at Treloar College.

Section 5: Impact

22. The mental effects of being infected with HIV, Hepatitis B and C are predominantly revolve around the stigma which is attached to these infections

and in particular, HIV. The stigma which was created by the media was that the infections were dirty and was transmitted as a result of immorality. As a result, I have suffered from 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.

23. I have difficulties with my long and short-term memory and concentration. I am unable to recall important dates and events that have occurred during my life, in particular the time I spent with my wife on during our honeymoon. It is know that untreated, aggressive HIV infection cause neurological problems.

24. The physical effects of being infected with HIV, Hepatitis B and C, are that I am always tired and lethargic. I have also looked very gaunt in the past. I try to maintain my weight, but it can be difficult. I also suffer from nausea and diarrhoea as a result of the HIV medication that I will now have to take for the remainder of my life.

25. A further medical complication which I believe results from my infections is epilepsy. I have no family history of epilepsy. I started having epileptic fits in 1981. It has been proven that HIV can cause epilepsy and I believe that my epileptic fits are a direct result of being given contaminated blood products.

26. 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.

27. 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.

28. 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 and was terminated prematurely.

29. A liver stiffness test (fibrosan) performed in December 2014 returned a score of 24.8 Kpa's, Cirrhosis was identified in my hepatology medical notes.

30. Finally, the third course of treatment I received for Hepatitis C infection was started on 27 August 2015 and 19 November 2015. This 12 week course comprised of Harvoni (Sofosbuvir / Ledipasvir) Ribavirin. Following treatment, I have now cleared the Hepatitis C virus.

31. I did not face any difficulty in accessing treatment for the Hepatitis C infection I contracted as a result of being given contaminated blood products, however over five years passed between being diagnosed with HTLV-3 (HIV) in November 1985 and being prescribed AZT in March 1991.

32. I do not believe there were any NHS approved treatments which were denied to me, as doctors and specialists seemed keen to offer me new treatments as they became available. However, patient trials of new, unapproved drugs which showed promise in treating my infections, were never offered to me.

33. The physical effects the first and second courses of Interferon and Ribavirin were severe and frightening. My entire body would be covered in a rash. Mentally, the first course of Interferon and Ribavirin made me angry and irritable. I frequently argued with my wife and got very frustrated. The rashes and swellings caused extreme itching and pain. These affects were mirrored during the second course of Hepatitis C treatment. I did not have any appreciable side effects to the third and final course of Hepatitis C treatment.

34. The psychological effects of AZT were dreadful. The AZT was a constant reminder that I had HIV because of the frequency I had to take them and the secrecy involved when collecting repeat prescriptions. The main physical effects that the AZT had on me was weakness, vomiting and muscle pain. I also suffered from headaches and lost many teeth. My current HIV medication (HAART combination therapy) also causes a loss of appetite and sickness, so I take daily nutritional supplements to compensate for my low food intake.

35. From early 1997, different drugs options were tried for the treatment of my HIV infection. Some caused extreme side-effects and were promptly stopped. I developed resistance to others antiretroviral drugs, before a four drug combination (HAART) therapy was found that has now kept my HIV viral load under control for many years.
36. The impact of being infected with HIV, Hepatitis B and C has had an adverse effect on my family and that of my wife and her family. My sister and her husband decided not to have any children. Although I cannot definitively prove it, I do believe it is in part because they may feel guilty that we have been unable to have children.
37. My wife, Tina is very loving towards me and incredibly supportive. We both wanted to have children and the fact that we have been unable to, is a great source of sadness to us both. By the time 'Sperm Washing' combined with IVF treatment became available in 2004, it was too late for us to be able to start a family. Tina's immediate family, were initially and understandably concerned, but have been very supportive and understanding throughout.
38. As a result of the stigma which is associated with having HIV, Hepatitis B and C, my wife and I decided to purchase a small bungalow in a quiet 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 HIV and Hepatitis C status.
39. When I left Treloar College I attended Scarborough Technical College and successfully completed a HND course in electrical engineering. I also attended various YOP schemes in electronics and computing.
40. Despite these qualifications, my infected status has hindered me in regards to my career. I wanted to become an electronics and software engineer, programming and creating masks for custom microcontrollers. However, due to the infections of HIV and Hepatitis C, ongoing epileptic attacks, severe haemophilia, combined with the medication I have to take with all their side-effects, I was unable to commit to even part-time work. Due to my epilepsy, I have never been able to drive which has severely limited my independence.

41. As I am unable to work, the financial effects have weighed heavily on me as I am unable to provide for my wife as I would have wanted. I would have been wonderful to purchase a property that met our needs and would be suitable to accommodate my disabilities. I would have liked to be able to help contribute more to general household expenses. Tina can only work part-time as she has to spend a great deal of her time looking after me.

42. 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.

Section 6: Treatment/Care/Support

43. The only treatment which I have 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.

44. Counselling has been made available to me, however it is not something I have wanted to participate in.

Section 7: Financial Assistance

45. I have received two lump sum payments. The first payment was the Stage 1 Skipton Fund payment of £20,000 which I received in 2001. I then received the Stage 2 payment of £25,000 because I had developed liver cirrhosis. Prior to 2005, I received £150 for each infection every month. However, I now receive £1,100 monthly. I also receive EIBSS support for my HIV infection.

46. The process of applying for a grant from the support trusts is extremely difficult. There are many hoops to jump through to make a claim. The

application forms are long and complex. The information which is required is means tested, very intrusive and monotonous.

47. 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 money, as the Skipton Fund refused to pay the full amount.

Section 8: Other Issues

48. I have suffered from Peripheral Neuropathy in my lower legs and hands since starting on HAART antiretroviral treatment for my HIV infection.

49. Lipodystrophy is also a problem for me, again associated to my HIV infection. When I get run down and depressed, I often get outbreaks of oral thrush.

Anonymity, disclosure and redaction

NR

I would like to give oral evidence to the Inquiry, NR

Statement of Truth

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

Signed

Dated

Anonymity, disclosure and redaction

48.

49. I would like to give oral evidence to the Inquiry,

Statement of Truth

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

51. Signed.....

52. Dated..... 27/02/2019