

Witness Name: David Gort
Statement No: WITN1244001
Exhibits: WITN1244002
Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DAVID GORT

I, David Gort will say as follows:-

Section 1. Introduction

1. My name is David Gort and I was born on the [GRO-C] 977. I live at [GRO-C] [GRO-C] Manchester, [GRO-C] I work as a freelance public relations consultant. I am married to my husband and we have lived together for 8 years.
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. [GRO-C] was diagnosed with severe Haemophilia A with a Factor 8 (FVIII) inhibitor. Within a year of my birth, I was tested and I was diagnosed with severe Haemophilia A. With treatment I eventually developed inhibitors.

4. I was treated with Cryoprecipitate at home by my local GP. I believe I was first given FVIII after a knee bleed in or about 1983. Treatment with FVIII was reserved for very severe bleeds as my body had developed inhibitors and it would reject the treatment. For severe bleeds I would be an inpatient at Royal Manchester Children's Hospital, Pendlebury (RMCH), as such I only ever received FVIII at this hospital.
5. In 1992, my care was transferred to the Royal Hallamshire Hospital in Sheffield (RHHS); they agreed to take me on early as GRO-C was being transferred there. When I became a new patient at the RHHS my parents received a letter, dated 15 June 1992 from Professor Preston stating that I was required to have a routine blood test for HIV and Hepatitis C (Hep C). I believe the blood test was taken around a month later. My parents were not given any more information about it.
6. Later that year, I attended an appointment at RHHS. I cannot recall if my parents were there, but I believe they may have been. I was told that I had contracted Hep C and that I should not be too worried. The doctor warned me about the risks of passing it on to someone else. He informed me of the importance of having protected sex and told me which bodily fluids to be careful about. I was provided with a booklet about Hep C, which told me how to manage the infection as best as possible, this included information on which foods to avoid.
7. The doctor also told me that I would have regular scans of my liver to check for lesions and liver cancer. He told me that treatment, Ribavirin and Interferon was available, but it was not very good. I believe I was provided with information that they had at the time.
8. I believe I was told I had Hep C very sensitively, but I was shocked that I was never told at RMCH. I consider that RMCH should have conducted routine tests and educated us about the risks of contaminated blood products.

9. I do not believe that the advice about drinking alcohol was communicated strongly enough. I was told to drink normal amounts of alcohol and to be mindful of my infection, so when I attended university I did not know the severity of drinking alcohol with Hep C. This is something that I had discovered much later on.
10. I do not know when I was infected with Hep C. However, in my medical records there is a letter dated 14/12/2017 from RHHS to Dr Marginson which states that I was infected prior to 1985.
11. I believe I have not contracted any other infections. I had regular tests for HIV and Hepatitis B (Hep B). I took part in a clinical study by RHHS about why haemophiliacs with inhibitors had not contracted HIV. I received an Information Pack, enclosed with a letter, dated 20/11/2009 that suggested that I had been exposed to HIV, but had not contracted it.
12. I am now treated for bleeds with Emicizumab and occasionally NovoSeven.

Section 3. Other Infections

13. I received a letter, dated 21/09/2004 from the Haemophilia Society stating that I had been exposed to variant Creutzfeld-Jakob Disease (vCJD). Later that year I had an appointment with the doctor and he told me that I did not receive the infected batch. I later received a further letter, dated 17/02/2009, which is exhibited at "WITN1244002" from the RHHS informing me that a patient with haemophilia had been found to have the abnormal prion protein that causes vCJD during his post-mortem. The letter stated that the patient had been treated in the 1990s with several batches of UK sourced clotting factors, including one batch of FVIII that was manufactured using plasma from a donor who went on to develop vCJD. The letter goes on to say: "The Department of Health has decided

that haemophiliacs who have received clotting factors made from UK plasma during 1980-2001 are at risk for vCJD and the box below shows the public health advice provided to reduce the risk of transmission." I worry about the possible implications for me, and others like me, who may also have been exposed to vCJD.

Section 4. Consent

14. I believe that I was tested without my parent's consent and knowledge at the RMCH. I had regular blood tests at RMCH, but we were never given any specific information about what they were testing for and what the results were.

15. There is a letter in my medical records, dated 24/08/1985 from RMCH to my parents which states that my blood tests are negative for HTLVIII. I believe this was the first time that my parents were told that I was tested for HIV. I do not know if my parents were told that I was being tested for HIV and I do not recall if I was told.

Section 5. Impact of the Infection

16. GRO-C are quite religious and practice Christian Science, which suggests that the mind has the power to heal the body. Although I am not religious, I believe that this teaching has helped me to remain positive. The only time I really thought about the infection was when I had blood tests and I would worry about the results and their consequences.

17. When I had Hep C, I was inexplicably tired a lot of the time. I had days when I felt okay, but I often hit a wall of tiredness that I could not explain.

18. In 2011 I started Interferon and Ribavirin treatment. I administered injections into my stomach and also had oral medication. During the treatment I was extremely

exhausted. I lost all my weekends and evenings due to extreme fatigue, which impacted my private family and social life. I also suffered from memory loss and found it difficult to concentrate. I would read paragraphs at work and not take in any of the information, this proved challenging when proof-reading documents. Unfortunately, this still affects me to this day.

19. As a result of my extreme fatigue and difficulty in concentrating, I was offered voluntary redundancy. I accepted this because I was unable to cope with the treatment. I eventually worked on a freelance basis. However, this had a financial impact in the interim period. I believe that I would still be working with the same employer or elsewhere in the public sector had I not had the treatment. Despite my health challenges I am ambitious. I would have hoped to progress my career in the public sector within the communications field. For example, one of my trainees is now Assistant Director of Communications, Policy and Research at a local authority. I am delighted for her. I too would have liked those career progression opportunities.
20. I also suffered from low platelets, which resulted in anaemia. As such, I had to attend the hospital every week to have my platelet count checked. My platelet count has now been low and they are only just beginning to reach a normal level.
21. I was warned that the treatment would also affect my emotions, which it did and I was prescribed anti-depressants. I did not think I would have to take them, but when I was on the treatment I could not control my emotions and felt either really high or incredibly low. I also became quite aggressive and felt angry at the world. The side effects lasted approximately a year and I did not suffer from them prior to my treatment.
22. As a result of the treatment, I also suffered from very itchy, dry skin patches where I had the injections and I took antihistamines for it. This is another side effect that has continued after treatment.

23. A month after I had completed the treatment, I was told that my Hep C had returned.
24. I believe that I have had medical complications, as a result of my infection with Hep C. In particular, I was diagnosed with cirrhosis in 2014. I also had an enlarged spleen and my immune system had been suppressed. I now have a flu-jab every year, but I still catch every cold and flu.
25. In 2014 I had a fibroscan and as previously stated I was diagnosed with cirrhosis. The results were 21.4 kPa. I was told by a hepatologist that it was not a big deal, because if I had developed liver cancer they would "just cut it out". I stopped seeing that specialist.
26. I was refused treatment with the new direct acting antiviral (DAA) drug, Harvoni, by the National Institute for Health & Care Excellence (NICE) as I had Genotype 4 Hep C. Guidance from NICE at that time stated that the treatment was not effective for Genotype 4 because it would take twice as long and was not always successful for my genotype. Alongside this, my cirrhosis was so severe that I was prohibited from some trials because it would affect the results.
27. My husband became very concerned and he obsessively tried to find a trial that I could join. He stayed up many evenings looking at trials and researching Hep C. Unfortunately at the time, Genotype 4 was less common and funding was not available for it.
28. In February 2015, I went to see Professor Graham Foster to discuss a course of treatment with Harvoni. I was referred from Sheffield to BARTS as Professor Foster was considered a leading expert in the field of Hep C and Haemophiliacs. During that consultation, Professor Foster told me to come back in April and wait for the new treatment to become available, as he believed the NHS would fund it

and at the time my liver was "holding up", although without treatment my results meant that there was a possibility that I would need a liver transplant in approximately 11 years. When I returned in April, Professor Foster told me that he did not know what was happening with Harvoni funding and he was not sure what the NHS were doing, or when it would be available. Professor Foster felt that, whilst he had told us to wait in February, if we had the financial means we should now consider self-funding given the uncertainty with the NHS.

29. After discussing the treatment with my partner we decided our only option was to fund the treatment privately given the very real risk of liver decompensation and heightened risk of liver cancer. I used £45,000 of the £50,000 that I received from The Skipton Fund to pay for a 12-week course of Harvoni plus Ribavirin. I completed the treatment and it cleared the Hep C. I also self-funded all of the travel to London for consultations with Professor Foster.

30. During the treatment I suffered from drowsiness, but this was only when I first administered it. As such, I took the treatment in the evenings. I did not suffer from any mental side effects and consider the treatment to have been plain-sailing in comparison to Interferon and Ribavirin.

31. The following year I had a further fibroscan and my results had dropped from 21.4 kPa to 11.4 kPa. Although the results indicated that my liver was still cirrhotic, it had drastically improved. Since then, my liver tests have improved and my platelets have increased. I had an ultrasound scan on the 08/11/2017 and it showed some coarse liver echo texture but there were no focal lesions identified.

32. If any new treatment becomes available for Hep C, I hope that those that have been infected through contaminated blood products will be given priority access. I would not want anyone to be excluded from treatments because they are not eligible, due to funding or any such issues. In particular, I would not want anyone

to experience what I did, having to fund the treatment myself, not to mention all the anxiety and stress the uncertainty that caused me.

33. With regards to the stigma associated with my infection, I have had horrible experiences when I have been treated by medical professions. Whenever I had blood tests I noticed a label on my file that said 'Category C Risk'. The nurses always put gloves on and were particularly cautious around me. In particular, I experienced a horrible incident when a junior doctor stuck himself with a needle that I was being treated with. I was woken up in the middle of the night and was taken into a side room, where I was questioned about my sexual partners and if there was a risk that I could have HIV.

34. When I was first diagnosed with Hep C, I did not tell anyone other than very close friends and family. I was aware that there was a stigma attached to the infections and I had seen how people that had contracted HIV had been treated; I did not want to experience this. During my treatment, I kept it very private from my work colleagues. Although I was not afraid that I would lose my job, I was worried that it would affect my relationship with the people at work.

35. When I was diagnosed with cirrhosis of the liver, I was sent for a gastroscopy to check for oesophageal varices. Due to my haemophilia I was treated with clotting factor (which lasts two hours in my system) prior to the procedure. Because my medical records indicate I may have been exposed to vCJD, the doctors spent an hour and a half deciding how to dispose of the scopes they used during my procedure, and the clotting factor had nearly expired. This made me very anxious about the procedure. No oesophageal varices were identified.

36. My husband has always been aware of my Hep C and potential vCJD exposure, however I know that my cirrhosis diagnosis significantly affected him. I found out that he had been going into work and breaking down due to the worry surrounding my prognosis. He had a lot to deal with when I was having the first course of treatment, as it changed my emotions and I became very moody and

aggressive. During this period we did argue a lot, but he was very understanding and has always continued to support me.

37. As a result of my infection, my parents have suffered a lot of guilt and additional pressure on top of my Haemophilia.

Section 6. Treatment/care/support

38. I have not been offered any counselling or psychological support. I believe that had the treatment been offered to me I would have accepted it, as this was a traumatic experience.

Section 7. Financial Assistance

39. In 2004 I received a £20,000 ex-gratia payment from The Skipton Fund after the hospital had informed me that I was eligible for it.

40. I have also claimed travel costs from the Caxton Fund. However, at this time I was very aware that they took into account household income. I believe they would have expected my partner to fund this had we moved in together at the time. As such, I was hesitant to move in with my partner. I do not think it was fair, as if and when you choose to live with a partner they should not have to foot the bill.

41. After I received my fibroscan tests results in 2014, I applied for the Stage 2 payment. It was difficult to give adequate evidence for this, despite the test results from the fibroscan. However, my consultant assisted me and completed the forms on my behalf. I received a payment in the sum of £50,000. However, as previously stated I used £45,000 of it to fund my second course of treatment.

42. Since then I have been receiving monthly payments. I initially received £1,200 a month and over the years and due to inflation, I now receive £1,500 a month.

Section 8. Other Issues

43. I have always struggled to get life insurance and travel insurance. As a haemophiliac you have to declare whether or not you have contracted infections from blood products. Although I have now cleared the virus, I still have to declare that I had Hep C and the end result is that they cannot offer any insurance or the premiums are prohibitively high.

Anonymity, disclosure and redaction

44. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

45. I am prepared to give oral evidence at the Inquiry if I am fit enough and it is required.

Statement of Truth

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

Signed.. GRO-C

Dated 25/1/19

Medical Summary

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Virology Results

16/07/1992	Hep A – Not detected
27/07/1992	Hep C – detected HCV Confirmation – detected
28/01/1993	Hep A – Not detected
10/06/1993	Hep B antigen – Negative Total core antibody – negative (no evidence of previous exposure to Hep B)
22/07/1994	HIV 1+2 Antibody – Not detected
19/03/1998	Hep C RNA – Detected by Roche
16/10/1998	HIV 1+2 Antibody – Not detected
23/12/2003	Hep C RNA - Detected

Significant Entries/Absent Entries

24/08/1985 Letter to patient's parents from D I K Evans – we have been sending blood samples away from the children with haemophilia and similar disease to see if they are at risk of AIDS. None of our patients has developed AIDS or has shown any signs of doing so, but all of us, both parents and staff, are anxious about the problem. The results are now coming through.

The blood tests on your child David show he is negative for HTLVIII. This is good news. We hope to be able to repeat the test every year or so to see if there is any change.

- 21/09/2004 Letter to patient from The Haemophilia Society– information about vCJD
- 22/12/2004 Letter to patient from M. Makris (RHHS) – further information about vCJD and subsequent conversation with Dr and patient. – “as discussed, I can also confirm that you have not received any of the implicated batches of clotting factor that have been prepared from plasma of donors who subsequently developed variant CJD”
- 25/09/2008 Statement of Consent – investigation of gene variants associated with resistance and susceptibility to HIV-1 infection in HIV-1 exposed but uninfected individuals with Haemophilia A – patient has agreed to the investigations
- 20/11/2009 Letter to patient from M. Makris – research study that patient may be interested in.
- 25/11/2011 Consent form – Hepatitis C and antiviral treatment in inherited bleeding disorders – patient has given his consent.
- 13/12/2017 Letter to Dr Marginson from R Maclean (RHHS) – review letter – patient has cleared Hep C virus. An ultrasound scan performed on 8 November 2017 revealed some coarse liver echo texture but there were no focal lesions identified. The scan showed him to have mild splenomegaly of 16cm on the scan but otherwise was unremarkable and was not changed from previously...