

Witness Name: DAVID PAUL MARKS

Statement No: WITN1687001

Exhibits: WITN1687002-4

Dated: JANUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DAVID PAUL MARKS

I, David Paul Marks, will say as follows:-

Section 1. Introduction

1. My name is David Paul Marks. I was born on [GRO-C] 1966 and I live at [GRO-C] London [GRO-C].
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. I have mild Haemophilia A with a factor VIII level of 11%. I was diagnosed with haemophilia from birth. [GRO-C]
[GRO-C]
My Uncle Eddie died of liver cirrhosis approximately 6 years ago as a result of contracting the Hepatitis C Virus (HCV) from contaminated Factor VIII (FVIII) blood products.

4. I am co-infected with the Hepatitis A Virus (HAV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV), type 2B. I was not aware that I had HCV until 1997 when I attended A&E with an injury. I was unaware that I had contracted HAV and HBV until I obtained my medical notes and records last year. I have cleared HAV and HBV naturally.
5. I was treated at the Royal London Hospital Haemophilia Centre under the care of Professor Jenkins and Dr Colvin. I refer to **Exhibit WITN1687002** being my Patient annual treatment record from the National Haemophilia Database. I am uncertain as to its accuracy as I believe that I was treated with FVIII before 1974.
6. I remember being in and out of hospital with various injuries/bleeds on quite a few occasions as a child. I refer to copy letters from the hospital dated 8th and 21st May 1975 at **Exhibit WITN1687003** confirming that I had been treated with a batch of Cryoprecipitate and/or Hemofil contaminated with Australian Antigen positive hepatitis the previous year. My parents were never told that I was contaminated with Australian antigen and/or at risk of contamination and I was not aware of it until I received my medical notes and records.
7. I remember being admitted to hospital in 1974 with a bleed. I was treated with what I believe was a FVIII product and I remember being very unwell almost immediately after treatment. I was so ill that I was kept in hospital for about one week. My mother was told that the hospital suspected that I had viral meningitis. I was put on a drip and they carried out tests to include a lumbar puncture. In retrospect I wonder whether my illness was a direct reaction to the contaminated product I was treated with. I eventually made a recovery and returned home.
8. My parents were not told about the risk of exposure to infection from blood products before treatment. My mother has recently confirmed to me that the risk was never discussed.

9. When I was 17 or 18 years old and the link between HIV/AIDS and haemophiliacs became known through the television adverts, I was reluctant to go to hospital for treatment unless it was absolutely necessary. I would leave minor bleeds and bruises untreated rather than risk unnecessary treatment.
10. I was told that I had HCV when I attended A&E for treatment to my hand. Dr Colvin learned that I was in A&E and called me to his office. He told me in a very matter of fact way that I had the virus. Referring to my medical notes, I believe the date was that of 13th October 1997. I had some awareness of what HCV was as my Uncle Eddie had been informed that he had HCV by then.
11. Dr Colvin said words to the effect that I should not "worry" because I was at the "top of the transfer list" and that there were "new treatments" now. My partner Leah was with me at the time, heavily pregnant with our fourth child. GRO-C I do not remember Dr Colvin saying much more to us than that. I was shocked and asked him why he had not told me sooner. He replied "you don't come to your appointments". I also remember Dr Colvin saying to me "by the way, don't drink, it's bad for your liver" as we turned to leave his office. He was extremely flippant and dismissive about the whole thing.
12. I would not have been informed that I had HCV had I not attended A&E in October 1997. I refer at **Exhibit WITN1687004** to a copy of a psychiatric referral letter dated 1st July 1998 from Dr Colvin. Dr Colvin cites the year 1990 as being aware of the 'likelihood' that I had HCV. My medical notes and records reveal that I had non A non B hepatitis prior to the date of 29th April 1988 and (according to a gastroenterologist) I had probably acquired the infection in about 1982 (Dr Colvin had previously told me 1984). In only being informed of the infection in October 1997, I was deprived for 15 years of the opportunity of making significant lifestyle changes, seeking treatment and taking steps to protect my family. I do not accept that I am to blame for this

because I missed some appointments. I was treated by the hospital during that period of time and I was kept in the dark about a very serious matter. Dr Colvin should have written to me and/or my GP and alerted me to the issue much sooner.

Section 3. Other Infections

13. Dr Colvin wrote to me on 2nd December 1997 to inform me that I am at risk of vCJD.

Section 4. Consent

14. Blood samples were taken from me from a young age. I was never told that I was being tested for hepatitis or HIV. I remember that they started taking more blood from me in or around the mid 1970s. At that time, I thought they were taking more vials of blood from me because I was getting bigger. My mother has confirmed to me that she was never informed that my blood was being sampled and tested for the purpose of identifying whether I had contracted any infections. She was not aware of any risk to me as a minor in being treated with FVIII.

15. The first time I knew I had been tested for hepatitis was when I was told that I had been infected with HCV in 1997. I only became aware that I had been tested for HIV when I read through my recently obtained medical records.

Section 5. Impact of the Infection

16. The impact upon me and my family of being told that I had HCV was an immediate one. Our daughter was born on GRO-C 1997. GRO-C

GRO-C

17. I met Leah in 1986. Our son (and fifth child) was born in 1999, the year Leah and I married. Before being told of my HCV diagnosis, I had the world at my feet. I had my own Haulage Company (a joint venture with my father-in-law) employing around thirty people. We had won an extremely lucrative contract for the haulage of all UK import/exports with a large Swiss company. Leah and I were about to buy our London home and become property owners.
18. The stress of my diagnosis and the effects of the clearing treatment I started the following year in 1998 changed everything. I had worked since the age of 15 and have not been able to work at all since the clearing treatment. I underwent a six month treatment course involving Interferon injections self administered with a pen. The side effects I experienced were absolutely horrendous. I had flu, sickness and diarrhoea. I had headaches, hallucinations and panic attacks. I only lasted for three months on the treatment and spent six months in bed because I felt so terrible. The interferon treatment was unsuccessful.
19. My thoughts, feelings and patterns of behaviour changed to the detriment of everyone around me. I became erratic, paranoid, mistrustful and generally unpleasant to be around. Dr Colvin's flippant comment warning me not to drink triggered something in me. I began to drink heavily and I was not a heavy drinker before. The haulage business went under as my father-in-law was unable to manage it for me.
20. My wife, Leah, left me in October 2002 as she could no longer cope with me. She left me suddenly and without warning, leaving me to try to raise five children alone. I loved her and did not see the end coming. I have a vivid memory that marks the end of our marriage. I remember standing outside our

home waiting for Leah to return. She appeared at the turning of our road and looked at me. She then turned and walked away again.

21. I was unable to cope as a single father although I tried. My in-laws took the first three and in or around 2007 Social Services removed the younger two from my care. I lost everything including my home.

22. Over the years I have been given conflicting information about the state of my physical health. I have been told that I have an enlarged, fatty liver and I have been told I have scarring to my liver. I have also been told that my liver appears to be functioning normally. I know in myself that I am unwell. I am exhausted just walking up the road. I suffer with chronic fatigue and am unable to sleep through the night. I am left with mental health issues in the form of a panic disorder. I suffer with chronic depression and anxiety.

23. I have a deep mistrust of medical professionals, having not only infected me with a serious virus but also having refrained from telling me about it for so long. I am unable to talk openly about my infection due to the stigma attached to it, and I know I wouldn't react well to hearing negative comments about it. Although my girlfriend knows about my illness, it isn't something we really talk about.

Section 6. Treatment/care/support

24. Last year I was put on a drug called Mavyret in a second attempt to clear the virus but this too was unsuccessful. There is a plan of a new course of drug treatment in the coming months. I currently take Mirtazapine to help with my depression. I was referred and have started psychiatric counselling last year.

25. Because of the risk of vCJD, two operations scheduled to take place have been cancelled due to lack of availability of disposable instruments. On the last occasion my operation was cancelled I was gowned with stockings and

had been given my premedication. I was desperate to have the operation because I had a spinal problem and I was in agony with pain to my right arm.

Section 7. Financial Assistance

26. I received a payment of £20,000 as a Stage 1 payment from the Skipton Fund in the early 2000's. I am considering making a Stage 2 payment claim on the grounds of mental health.

27. I currently receive monthly payments from EIBSS.

Section 8. Other Issues

28. I believe a large proportion of my medical notes and records to have been destroyed. I remember being in hospital when I was younger and my medical records would appear stacked high on a hospital trolley because of their volume.

Anonymity

29. 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. I would like 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

18.2.19

MEDICAL SUMMARY

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

- 1974 Treated with cryoprecipitate and/or Hemofil contaminated with Australian Antigen positive hepatitis (*Exhibit WITN1687003*)
- 10.08.1978 HBV negative (*virology*)
- 07.06.1982 HBV negative (*virology*)
- 28.05.1985 "Herpes and candida probably related to heterosexual rather than homosexual activity. No evidence of AIDS". HTLV test result awaited. "Anti HB s > 120. No need to vaccinate." (*medical records*)
- 11.12.1986 "Treated only with 8Y in past. Anti HIV negative. Anti HBs Ag positive" (*medical records*)
- 29.04.1988 "His liver function tests have been marginally abnormal, presumably due to mild non A non B hepatitis in the past." (*letter Dr Colvin to Senior Medical Officer, [GRO-C]*)
- 20.05.1993 "the HIV test has been consistently negative" (*letter Dr Colvin to GP*)
- 13.10.1997 "Never jaundiced. Well in himself.... No HCV test result. Liver and spleen not palpable.... I have explained the likelihood of HCV infection.... I have also mentioned the very small risk of sexual transmission of HCV.... Needs.... HCV review and counselling."
- 17.10.1997 Informed patient and wife of risk of sexual transmission of HCV (small). Both read HCV leaflet. [GRO-C] (*medical records*)
- 27.10.1997 "HCV PCR positive" (*medical records*)
- 31.10.1997 "I have informed Mr Marks. [GRO-C] (*medical records*)
- 17.11.1997 "He came into hospital on 13th October, having fractured his right hand in a fight and this has now recovered" (*letter Dr Colvin to GP*)
- 02.12.1997 Informed at risk of vCJD (*letter Dr Colvin to David Marks*)
- 04.03.1998 HCV infection probably acquired in about 1982 (*Dr C P Swain, Consultant Gastroenterologist to Dr Colvin*)

- 02.06.1998 "He is still finding it difficult to cope with the hepatitis C diagnosis & is drinking heavily. I have discussed seeing a counsellor & he has agreed to be referred to one." (*Medical notes, Haemophilia sister*)
- 01.07.1998 Psychiatric referral to Dr Palazidou made by Dr Colson (not attended) (**Exhibit WITN1687004**)
- 01.12.1998 "was on interferon for 3 months until September 98" (*medical records*).
- 07.01.2003 Reports of suicide attempts "problems with mental state started after finding out about hep c positivity".
- 05.11.2007 Operation delayed due to "lack of disposable instruments" (CJD) earlier that year. (*letter hospital registrar to GP*)
- 19.02.2010 Evidence of 'hepatitis B' infection with detectable anti Hb core antibody. Hep C viral load is 6.88 ... Applied for part one of Skipton Possible part two depending on whether we pursue a biopsy. (*copy letter Dr Dan Hart, The Royal London Haemophilia Centre to GP*).
- 16.05.2011 Cirrhosis of liver (*medical notes and patient admission/information sheet*).
- 17.05.2011 Normal ultrasonic appearance of liver (*Final Report*)
13.
03.2013 Disc operation cancelled on day of operation (CJD)