

Witness Name: Mark Harding

Statement No: WITN1271001

Exhibits: WITN1271002-5

Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARK HARDING

I, Mark Harding will say as follows:-

Section 1. Introduction

1. My name is Mark Harding. I was born on 1977 and I live at
 Derbyshire, with my wife and two children.
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.
3. I cannot be certain about some of the dates of my treatment and other events because of the passage of time.

Section 2. How infected

4. I was diagnosed with severe Haemophilia A (clotting factor level 0%) when I was around 18 months old.

5. Initially I was seen in Burton-Upon-Trent and the doctor there assumed that my parents had been beating me as a baby because of my bruises but after my parents demanded a second opinion I was tested for and diagnosed with haemophilia at the Derby Royal Infirmary.
6. I was seen by Dr Mitchell at Derby Hospital as a child and am currently under Dr McKernon.
7. Initially I was treated with cryoprecipitate and started home treatment when I was about 8 or 9.
8. When Factor VIII first became available, the staff at Derby Hospital were very reluctant to put me on the new treatment. They kept on pushing it back despite the fact that most other haemophilia centres were using it.
9. I believe that the first time I ever received Factor VIII was when I hurt myself whilst on holiday in Bournemouth. This was administered quickly via a syringe, not the usual drip method, so I assume that this was the newer treatment at the time. I understand that Bournemouth Hospital has no records relating to this treatment.
10. I was also treated at Bangor Hospital and my treatment here was very haphazard. I recall that the doctor wasn't even able to find a vein to administer the product. I eventually had to inject it myself when it proved too difficult for the doctor, despite the fact I was only a child.
11. After this, Derby Hospital informed my parents that they had run out of Cryoprecipitate, and that if I wanted to continue to receive treatment at Derby I would be moved to Factor VIII and my parents would have to sign a waiver protecting the hospital from any liability. It was either they sign the waiver or Derby would refuse to treat me; it was as simple as that. My parents therefore had no other option than to sign the waiver.

12. As soon as I started receiving Factor VIII from Derby, I started having to attend the hospital several times a month for tests. My parents were told these tests were to check if the Factor VIII was working effectively; there was never any reference to Hepatitis C or HIV. We were told that these tests were going to be used in a medical report; however we haven't heard anything about this since.
13. My medical records show that I was tested for Hepatitis C on the 23 April 1990 but the virus was not detected. I was not aware of this test or its outcome. I was apparently tested again on the 15 April 1993 however the results of this test have never been found. There is now shown to me marked **WITN1271002** a copy of the correspondence from the hospital regarding these results.
14. In or around 1995 I was called into Derby Hospital where I was told that I had Hepatitis C. I was told it could cause me problems when I was older but it was nothing to worry about for the time being. They said that I had got it from contaminated blood products, but I was lucky because at least I didn't have AIDS. The hospital had clearly known for some time that I was infected as evidenced by the letter exhibited at **WITN1271003**.
15. I didn't know what it all meant or what was going to happen to me. I was familiar with the HIV adverts on the television and I was worried that I too would turn into one of the skeletal figures I had seen on TV. In an attempt to reassure me, I recall someone at the hospital telling me that I had already had the virus for 'ages' and I didn't have any problems, so I shouldn't worry about it.
16. I couldn't tell people that I had Hepatitis C because of the stigma of the disease; it was an infection associated with drug users. My parents thought it would be better that I didn't tell anyone because they were worried about the reaction I would receive.

17. The only people I really told growing up were girlfriends. It was tough telling girlfriends that I had a transferable illness that could affect my life or could kill me in 3 years.

18. I received little advice about the illness. The only information I ever received was because I went to the doctors and asked them myself. I was initially told that it could only be transmitted through blood. When I asked if it could be spread through sexual intercourse, I was told that due to the volume of fluid required to do that I would either have to be a bull or a racehorse.

19. I note from the letter dated 14 November 1995 in my medical records (exhibited as **WITN1271004**) that Dr McKernan believes I was infected by Cryoprecipitate rather than Factor VIII concentrate.

Section 3. Other Infections

20. I received a letter in 2004 advising me that I may have been exposed to vCJD. It has never really been discussed with me as I was told by my doctor not to worry and that I didn't have it. My records also contain an earlier letter dated February 2001. I do not recall ever seeing this letter. Both letters are exhibited at **WITN1271005**.

Section 4. Consent

21. I was a child when I was being tested so was never informed or consented to what I was being tested for.

22. My parents were not made aware I was being tested for Hepatitis C or HIV until I was informed of my diagnosis.

23. We can only assume that the frequent tests I was having when I moved on to Factor VIII were for these diseases and that we were simply never informed about this.

Section 5. Impact of the Infection

24. I definitely think my infection had a big impact on my education. All of my school reports stated that I had a lot of promise but just couldn't stay focused or remember what we had been learning. We could spend 8 weeks on a topic and when came to the exam a month later I had forgotten everything.
25. When I was preparing for my GCSE exams revision was a real struggle. I couldn't remember anything long term and in the end just revised for things the night before the exam as if I tried to remember things for longer than that I simply forgot them. As a result of this I got a D for my English GCSE and had to resit it twice to get a C.
26. I've never bothered reading books because I know that I wouldn't be able to recall what's happened and what I have already read. I have the same problem with TV series. I can put a film on that I haven't seen in a year and I can't remember that I've ever seen it.
27. My brain fog and memory problems have persisted despite being 'clear' of the virus. I have apps and alarms on my phone to remind me about everything. For example, if my wife asks me to go to the shop one day but I haven't set an alarm to remind me, I completely forget to go. I've forgotten my Google password 3 times in the last 2 weeks as I'm so forgetful.
28. In 1995 I attended Burton Technical College to do a National Diploma in Computing.
29. I am now the manager of IT at Burton College Technical College where I have worked for 20 years. It is the only place I have ever worked. I started there in 1995 to do my National Diploma in Computing. I then started to work on their help desks part time, eventually working my way up to technician, team leader and now to manager. Because of my memory issues I have had to cover my room in post-it notes to remind me how to do everything.

30. I am too scared to apply for other/better jobs because I am very comfortable with the help and support from my current colleagues. They understand my limitations and illness and try to make my life as easy as possible.
31. I only sleep for about 4 hours a night because I find it extremely difficult to get to sleep. This means that I get tired at around 10am every day.
32. My mouth is full of fillings because my teeth are so poor. I have always taken very good care of my teeth and I have heard from numerous people within the Hepatitis C community that they have had similar problems. I am therefore confident that my dental problems have arisen as a result of my infection.
33. I was first treated with Interferon in an attempt to clear the virus in 1995 at Queens Hospital in Nottingham. I was taught to do the Interferon injections myself.
34. This treatment made me feel absolutely terrible and I pointed this out to my doctors, but as I was already not feeling great at this time it appears from my notes that the hospital assumed there were no side effects; this was not the case. I had joint aches and pains, headaches and severe flu-like symptoms when I started the treatment, although this did tail off slightly towards the end, after many months of suffering. I was always tired and fatigued, and just generally felt awful.
35. When the treatment was finished, I was told that it had made a bit of an impact but it had not cleared the virus.
36. In 2003 I was put on Interferon and Ribavirin. This gave me the same side effects as my first course of treatment, although possibly not quite as severe, although again this has been omitted from my medical notes. Once again, the treatment was unsuccessful in clearing the virus and I was told there were no other options available for me; I would just have to live with it.

37. A few years later I was informed about potential clinical trials, which I put myself forward for. I was not put on any of the initial trials as I was told they were only being given to those with more severe liver disease. A short while later, after I had a Fibroscan which showed that I had a very high count which could easily lead to cirrhosis, I was told there was a trial available for me.
38. It was a 12 week course which involved taking several different medications. According to my records it was called 'Abbvie'. Every week I had to go to the hospital to pick up the medication. Within a month of starting the treatment I was told that the virus had 'cleared'.
39. Although I am 'clear' of the virus, I disagree with the use of this word as I consider the virus is dormant. There is no way of knowing for sure if the virus will come back, which is supported by the fact that I am not allowed to donate blood. I will also continue to be affected by the damage done to my body and my teeth, and I believe I have become conditioned to sleep-deprived nights, constant itching, depression and generally feeling unwell.
40. My wife says that I sometimes have mood swings and can be a bit down. She doesn't think I seem my usual self and she asks me if I am depressed and if everything is okay. She has suggested that I speak to a counsellor however I am probably too proud to do that. I always find excuses not to leave the house or see friends, and would rather stay in by myself and do my Lego models as this is something I can do on my own without having to interact with others or leave the house. This is something I enjoy and am able to do on my own in the early hours of the morning if I cannot sleep.
41. I have never been able to get life insurance and the only quote I ever received was for £400 per month.
42. When we applied for our mortgage I was told I needed life insurance. We filled in forms with the bank for them to insure my life but this was rejected when they found out about my Hepatitis C. After speaking to a financial advisor he told me to tell the bank that they would be in breach of certain relevant laws

and regulations by refusing me a mortgage/insurance. It went to someone high up at the bank who said as a one off they could give it to us but only because my wife had life insurance. This made me feel like an outcast and that I have to justify and fight for everything that a 'normal' person wouldn't have to.

43. I also have to pay a lot more for travel insurance and have been told there are several countries I wouldn't even be allowed to enter. The only reason we're able to go to certain places and afford insurance is because my wife has blanket insurance through her job. I am therefore considered to have an 'ongoing illness' as I have had Hepatitis C for so long.

44. It was difficult being infected as a parent of young children. I was always worried about infecting them when they were growing up and would be too scared to give them a kiss goodnight if I had cut myself shaving or had a severe mouth bleed due to my deteriorating gums which left my children crying as they thought I didn't love them because I couldn't give them a goodnight kiss. This made me feel like a bad parent and I believe affected the way in which I bonded with my children in their baby and toddler years. They still struggle to understand what is happening and are upset when they know that their dad is in pain or unable to go out with them to play or do the activities all other parents can do.

Section 6. Treatment/care/support

45. I haven't really felt like I have had to fight for my treatment, although it is frustrating that I was seemingly not offered any medical trials until I had developed cirrhosis.

46. I have not been offered counselling at any stage. My wife believes that this is something that could benefit me.

Section 7. Financial Assistance

47. I was told about the Skipton Fund through the hospital. I was made to sign a waiver to receive the initial payment but I had no other option than to sign it as I was told I wouldn't receive anything if I didn't.

48. I was unable to receive the Stage Two payment from Skipton as they considered my liver damage to be just under the level required to be eligible.

49. I received a £500 winter fuel allowance from Caxton Foundation. However, claims to this Foundation was means tested and as I was working I wasn't able to claim anything else from them.

50. I had heard you could claim for household appliances, respite holidays etc. However, of everyone we had spoken to we were only aware of one person who received anything, which was a contribution to a washing machine. I therefore never bothered to apply for anything as it felt like a begging pot rather than support.

51. I applied to EIBSS for the £300 per month payments. The scheme was then increased to £1500 per month which I currently receive.

52. The application forms for EIBSS were very confusing so I contacted my doctors to help me with them. They said as they had received so many requests they were running a clinic to assist the patients but that it was difficult for the doctor to comment as he only normally saw his patients once a year for a check up for. The clinic that the hospital ran was therefore done on a private basis and the appointment had to be paid for.

Section 8. Other Issues

53. I want to know how and why so many important documents from the medical records of haemophiliacs are missing and life changing test results have vanished.

54. In other countries people have been found guilty in criminal courts in relation to contaminated blood, but here no one has taken responsibility. Someone needs to be held accountable.

55. It has taken so long to get to this stage and even now it is an extremely slow process. It feels like if the Government drag their heels long enough then we will all be dead and there will be no one left to hear the truth.

56. Ultimately, I think it is essential that the Inquiry gets to the bottom of what happened, as although it is too late to help me, the NHS needs to learn its lesson and ensure that this can never happen again to other people in the future.

Anonymity

57. I would like my address to be redacted from my statement. Other than that I do not require anonymity.

58. I would give oral evidence if the Inquiry believed it would be useful.

Statement of Truth

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

Signed. GRO-C.....

Dated. 27/12/18.....

MEDICAL SUMMARY

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

- 23.01.85 HTLV III Neg
Hepatitis B Neg
- 27.11.89 Letter from Dr Mitchell, Consultant Haematologist, to GP. It is important that he should not be receiving unnecessary Factor VIII as whilst there is no longer fortunately any risk of transmission of known viruses, it is still a foreign protein and one needs to restrict its use to genuinely bleeding episodes.
- 09.03.90 HBc Ab by ELISA negative
- 23.04.90 Hepatitis C serology (result from reference laboratory) anti HCV not detected (EIA)
- 12.06.92 HBs antibody by ELISA not detected
- 20.04.93 Antibody to HIV negative
HBsAg by ELISA Negative
No Hep C result
Further report to follow
- 19.04.94 Letter from Dr Gould (Haematology) at Derbyshire Royal Infirmary (DRI) to GP. He is, as yet, unaware of the diagnosis of Hepatitis C and we will be broaching this in the near future.
- 07.07.94 HBsAg by ELISA negative
HBs antibody by ELISA not detected
Further report to follow on Hep C

07.07.94 Hepatitis C antibody – positive by EIA

06.04.95 Letter from DRI to GP.....this was an opportunity to review his haemophilia and also to discuss hepatitis C....We had a long discussion with him and his mother about hepatitis C. His mother brought up the topic as she had been to a hepatitis C day organised by the Haemophilia Society earlier this year. Mark is hepatitis C positive, as are nearly all haemophiliacs who were exposed to clotting factor concentrate pre 1985. Most such patients will have developed chronic hepatitis and about a fifth will progress to cirrhosis. Of this fifth a minority will develop a hepatocellular carcinoma. Overall however, although the instance of hepatocellular carcinoma is increasing in these patients, I have stressed to Mark and his mother that only a minority of patients run into serious liver problems. At present the only proven treatment of any value for hepatitis C is Interferon. This however does not give brilliant results. Of those who receive Interferon, 50% normalize their liver function tests and PCR, however of this 50% only a half have a long lasting response.....We know there are certain hepatitis C genotypes that have a poor response to Interferon with notably genotypes 1A and 1B.....We also need to bear in mind that Interferon, whilst not having any serious long-term side effects, can sometimes make people feel pretty rotten when taking it.

06.06.95 Letter from DRI to GP. We discussed hepatitis C again, Mark has a very laid back attitude to this and is not particularly worried about it. He did ask how hepatitis C could be transmitted. I reassured him that this is usually only via blood products or sharing needles. We discussed the chances of sexual transmission, which are very low, and that the partners of hepatitis C positive people have only a slightly increased incidence of hepatitis C positivity compared to the general population. Should Mark develop a long term relationship this would be something he needs to discuss with his partner. For more casual relationships, however, I strongly suggest that Mark uses a condom.

- 07.06.95 Antibody to HIV negative
 HBsAg by ELISA negative
- 14.11.95 Letter from DRI to GP. I saw Mark with both his parents in clinic and we had a long discussion about Hepatitis C, covering all the relevant points. Mark's father was concerned as to how he acquired Hepatitis C as he didn't have Factor VIII concentrate before 1985. However, he did have cryoprecipitate and I am sure this was the source. Mr Harding was also concerned that around 1985 he was put on a trial product and therefore had monthly blood tests. He wanted to know why Hepatitis C wasn't picked up in these. I pointed out that these would have been routine LFTs which could well have been normal at that point and in fact we have a value from the mid 80s and they were normal. He was also a bit concerned that Mark and his family hadn't been told that he was Hep C positive when we originally had a positive test. However, looking back through the notes he originally had a Hep C antibody test in 1990 which was negative and a repeat test in 1994 which was positive. We discussed the pros and cons of Interferon and Mark and his family are aware that only a quarter to a third have a long term response and we also discussed the potential side effects, including muscle aches and pains, depression and flu-like illness.
- 20.12.95 Letter from DRI to GP. He has now been on Interferon for four weeks. He felt very tired the day after he started Interferon but apart from that he feels his usual self. He has had no tiredness, no depression, no flu-like symptoms and is coping with giving the injections himself very well. He says he is happy to continue.
- 23.01.96 Letter from DRI to GP. He feels very well in himself and has had no side effects from Interferon....He has now been on Interferon for two months and I have taken some blood to check his LFTs and also to freeze down some citrate for future studies.

- 26.01.96 HBsAg by ELISA negative
Anti HAV by ELISA negative
Antibody to HIV negative
HBs antibody by ELISA not detected
HBc Ab by ELISA negative
- 16.02.96 Letter from DRI to GP. He is tolerating the Interferon very well and has no side effects whatsoever. He has now completed three months of treatment and I have therefore bled him to repeat the viral load which will be sent to Edinburgh this week. On the basis of this result we will decide whether to we should continue Interferon or not.
- 19.03.96 Letter from DRI to GP. We now have the results of the repeat hepatitis C PCR and unfortunately the Interferon has made very little difference...I have therefore doubled his dose of Interferon and hope this does not cause him any symptoms. We will do this for 3 months and repeat the PCR again. If it has still made no difference we will probably abandon Interferon.
- 30.04.96 Letter from DRI to GP. He has no side effects despite increasing the dose of Interferon...
- 12.09.96 Letter from DRI to GP. The most recent PCR showed no change from the original PCR, ie the Interferon has had no impact on this. We know that only 17% of haemophiliacs on recent studies responded to the Interferon so this is not all that surprising. Mark was quite realistic about this and does not appear to be too disappointed that the Interferon has not worked. For now we will simply observe him and will consider further intervention along the lines of Ribavirin plus or minus Interferon in the not too distant future.
- 22.10.97 Antibody to HIV negative
Anti HAV by ELISA negative
Anti HCV detected by EIA

HBsAg by ELISA negative

- 12.11.97 Letter from DRI to GP. We had a discussion with his partner about hepatitis C and I told her that the risk of transmission of hepatitis C sexually is very low, and the sexual partners of hep C patients have only a slightly higher incidence of hep C compared to the general population. I did however advise Mark to continue with safe sex methods until this becomes a long term relationship, when he needs to discuss this matter again with his partner.
- 18.11.97 Letter from Dr McKernan (Haematologist) to J Freeman (Gastroenterologist) at Derby City Hospital. His ALT has been intermittently marginally elevated HCV PCR positive, genotype 1b.....
- 16.12.97 Letter from J Freeman (Gastroenterologist) to Dr McKernan (Haematologist) at DRI. I think the best approach would be for him to have a liver biopsy to establish what his Kendell score is to see whether he needs Interferon.
- 17.06.98 Antibody to HIV negative
Anti HAV by ELISA positive
HBsAg by ELISA negative
- 12.10.98 Liver biopsy.
- 17.12.98 Letter from J Freeman to Dr McKernan. His recent biopsy showed he has mild chronic persistent hepatitis.
- 17.12.98 Microbiology.. Antibody to HIV: negative; Already known to have Hepatitis A antibody (17/6/98) and Hepatitis C antibody (22/6/97).
- 25.03.99 Reverse transcriptase PCR for HCV RNA positive
- 13.01.99 Knodell biopsy score: 4

- 09.06.99 Antibody to HIV negative. Please see report 2/12/98. Known HepA antibody pos. HepB immune. HepC antibody pos.
- 24.11.99 Negative HIV test
- 04.01.01 Negative HIV test
- 10.01.01 Letter from DRI to GP. Mark found the first biopsy difficult to tolerate and I think it would be reasonable to proceed to some treatment without a further biopsy.....
- 05.02.01 vCJD letter.
- 28.03.02 Negative HIV test
- 25.07.03 Letter from Dr Freeman to GP. I reviewed Mark today and am glad to report he is very well in the ongoing PEG Ribavirin trial at QMC.
- 20.09.04 vCJD letter.
- 16.02.05 Letter from DRI to GP. He has now had two courses of Interferon, one as a research course of pegulated Interferon/Ribavirin and one standard Interferon. He did not clear his virus.
- 28.01.08 Letter from Derby Digestive Diseases Centre to GP. He remains very well and his ALT is only 65. I have explained to him his liver biopsy in the past only showed fibrosis score 1, hence we will continue to monitor him here on a yearly basis and I suspect there will be new treatment available within the next 5 years.
- 13.06.09 Letter from DRI to GP. I spent some time talking to Mark and his partner as I think they wish to try for children but I suggested that his

partner have some anti Hepatitis C anti body status checked GRO-C

GRO-C

- 08.03.11 Letter from Dr McKernan to Patient regarding the Skipton Fund. We are currently reviewing Hepatitis C as part of the Hepatitis C look back exercise, which you may have heard about through the haemophilia society. You may also have heard that there have been some changes to the compensation rules. I attach some information about the changes....
- 13.05.15 Letter from Derby Digestive Diseases Centre to GP. I am pleased to say that your liver function tests when they were done at the beginning of April are only slightly raised....there is no evidence on your blood test that you have significant liver disease.....Unfortunately this does mean at present that you are not really eligible for any of the new treatments coming out but you will be in the future....
- 14.04.16 Clinic notes. Fibroscan 11 Kpa.
- 14.04.16 PCR for Hepatitis C RNA: Detected
- 04.05.16 Letter from Derby Digestive Diseases Centre to GP....He is very well informed about the new medication which is available through NHS England for hepatitis C. At present we have a waiting list for this medication and priority is given to people with more advanced liver disease. A FibroScan was performed today....and it showed a score of 11 Kpa which is borderline on cirrhosis of the liver. I think this will give Mark priority on our waiting list....
- 08.07.16 PCR for Hepatitis C RNA: Not Detected
- 20.07.16 PCR for Hepatitis C RNA: Not Detected

- 21.09.16 Letter from Derby Digestive Diseases Centre to GP....reviewed...in clinic today on week 8 of his 12-week course of the Abbvie regime. His recent bloods are stable and his PCR at weeks 2 and 4 are undetectable.
- 17.08.16 Letter from Derby Digestive Diseases Centre to GP. I commenced this gentleman on a 12 week course of the new direct acting agent drugs by AbbVie....Side effects and treatment process were discussed in detail. The side effects with this treatment are quite minimal, however, you can encounter headaches, nausea, fever, fatigue....
- 15.09.16 Letter from Dr McKernan to GP. He has just completed treatment for hepatitis C and tells me he is so far clear.
- 23.01.17 Letter from Dr McKernan to GP. He was first tested for Hepatitis C in April 1993 but I cannot find the result of the test in his notes and I have looked on iLab and the earliest report I can find is from 1997.
- 28.04.17 Letter from Derby Digestive Diseases Centre to GP. This gentleman was discussed at the Viral MDT. He has recently been treated and achieved a sustain virological response to viral hepatitis. The discussion at the MDT was regarding whether he needs ongoing surveillance with a FibroScan of 11.8 as he was slightly in the grey area....The plan would be to repeat his FibroScan in 6 months time and review the results and discharge at this stage if appropriate.
- 23.11.17 Letter from Dr McKernan to patient to notify of new EIBSS.
- 24.01.18 Letter from Gastroenterologist to GP. I met with Mark today to assist in completing his EIBSS claims form....he was infected with Hepatitis C when receiving contaminated Factor VIII as a teenager and only within the last 12 months were we able to offer successful treatment after 2 failed attempts with interferon based therapy over many years. Although he has not received any of the diagnoses associated with

autoimmune complications of treatment of viral infection, we were able to complete the form on the grounds of chronic anxiety, lethargy, poor concentration and insomnia. He has managed to continue to work in IT at Burton College but his other activities are severely curtailed by these symptoms which I think are highly likely to be secondary to the chronic infection he suffered and previous attempts at treatment with interferon based therapy.