

Witness Name: **GRO-B**

Statement No: WITN1049001

Exhibits: WITN1049002 - WITN1049006

Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:-

Section 1. Introduction

1. My name is **GRO-B** I was born on **GRO-B** and I live at **GRO-B**, with my wife. We have been married for **GRO-B** years and have two daughters and 4 grandsons. I am a retired **GRO-B** **GRO-B** and my wife was a **GRO-B**
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2009. I am aware that my wife **GRO-B** is also providing a witness statement to the Inquiry.
3. This witness statement has been prepared without the benefit of access to my 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

4. I suffer from mild Haemophilia A and have a clotting factor of 30%. I had some teeth removed when I was about 5 years old and they could not stop the bleeding but I only first realised that I had Haemophilia in 1963 when I was [GRO-B] years old after my appendix was removed [GRO-B] Hospital. At Lewisham Hospital the Consultant sat me down and said '*let's start from the beginning*'; we then talked about how having Haemophilia would impact on my life. I had a list of things that I was not allowed to do anymore because it was dangerous, including playing cricket which I loved. He also talked to me about changing my job as I was a jig and tool maker and as a result moved into to jig and tool design. After the meeting I was absolutely shell shocked.

5. I was treated with plasma for a bleed to do with my toe at Kingston General Infirmary in Hull in 1976. Then on 21 May 1982 I was given 3 packs of Fresh Frozen Plasma (FFP) (6176147, 6176133 and 6176123) and Armour Factor VIII concentrate (FVIII) (batch number V52309) and on 22 May 1982 was given further Armour FVII (batch number V52309) and NHS concentrate (batch number HLA2928) as seen in the letter dated 15 June 1982. I was also given FVIII in 1987 and 1989. I exhibit my Summary of Treatment Card, the letter dated 15 June 1982 and my UKHCDO Patient annual treatment records at WITN1049002.

6. I have been mainly treated at the Norfolk and Norwich University Hospital under the care of Dr Black, Dr Lesley, Dr Wimpres and Dr Turner. However, I moved away from [GRO-B] to [GRO-B] for about 4 years between 1976 and 1980 when I was under the Hull Haemophilia Centre. I then moved back to [GRO-B] around 1980 and exhibit a notification from the Norfolk and Norwich to Miss Spooner at Oxford Haemophilia Centre for inclusion in the National Statistics at WITN1049003. I moved to [GRO-B] Yorkshire in 2009 after I retired and have since been treated at the York and Leeds Haemophilia Centers.

7. I believe that I was infected in 1982. This was suspected by Dr Black in a letter dated 17 May 1982 (which I believe should have been dated 17 June

- 1982) and confirmed in a letter from my GP to The Scottish Mutual Assurance Society dated 11 August 1987. This also ties up with a normal blood test that I had on 24 January 1980 which compare with the blood test on 14 June 1982 which shows very high levels of AST and ALT and is noted as '*Inf Hepatitis*'. My blood test results of 15 June 1982 are marked '*HIGH RISK*'. I exhibit both these letters and blood tests at WITN1049004.
8. No explanation was given beforehand about any risk associated with FVIII concentrate.
 9. I was infected with Non-A Non-B Hepatitis, which was later known as Hepatitis C (HCV) as a result of being given contaminated blood products. I have genotype 3a.
 10. Shortly after I had the circumcision operation in May 1982 I was at home and started to feel ill. My wife, who was [GRO-B] rung Dr [GRO-B], our GP and told him that I was not very well. Dr [GRO-B] thought it may have been a urine infection, so I went in for a test in the middle of the week. On Saturday lunchtime my wife and I were out in [GRO-B] and I felt ill. We went home and my wife noticed that I was turning yellow, so she guessed I had Hepatitis and rang the surgery. Dr [GRO-B] came to the house and he also believed it was Hepatitis. I just deteriorated from then on.
 11. I remember that I found out I had Hepatitis C in or around 1995 from [GRO-B] who was a Haemophilia nurse and also a good friend of my wife. [GRO-B] came round to our house after work one day and told me. I don't remember her explaining how serious HCV was.
 12. Prior to finding out I had HCV, [GRO-B] always insisted that when I had a blood test I took a copy of the results home with me. When I changed my GP to Dr [GRO-B], [GRO-B] asked for the test results and he asked '*why do you want them, are you going to sue us?*' [GRO-B] asked '*why would I sue?*' Dr [GRO-B] just smiled. He would not let me see the results.

13. I was not given adequate information to help manage the infection. I feel very strongly that more information should have been provided to me about the infection.

14. I believe information should have been provided to me as soon as the NHS knew something was wrong. I can see from my medical records that the first positive blood test for HCV was on 31 March 1994 and there is also a letter from Dr Wendy Clarke to my GP Dr GRO-B dated 27 June 1995 referring to a clinic appointment when she advised me that I was Hepatitis C positive, and I exhibit both of these at WITN1049005.

15. My wife and I were not provided with any information about the risks of others being infected as a result of the infection. I think they assumed as my wife was a nurse it was not important to tell us as she would already know. However, my wife did not realise as she thought it was only as dangerous as what she came into contact with everyday.

Section 3. Other Infections

16. I do not believe I received any other infections besides HCV.

17. From my records I can see a copy letter from Dr Turner to me dated 22 September 2004 forwarding information from the Health Protection Agency, however, my Patient vCJD Exposure Assessment Form signed 28 September 2004 indicates that I did not receive any of the batches listed.

Section 4. Consent

18. I know that I was tested for HIV. When they told me I needed a HIV test they said it could go against me when I applied for insurance. From my UKHCDO records I can see that a sample dated 14 February 1985 was tested on 8 August 1986 and was negative.

19. I was not aware that I was tested for Hepatitis B on 16 September 1982.

20. I was not aware at the time that I was tested for HCV on 31 March 1994.

Section 5. Impact of the Infection

21. When I was infected in 1982 and had jaundice I was very unwell. The first 2 or 3 months were horrendous. It was a terrible strain. I had very bad lows and very few highs. My wife took 2 weeks unpaid leave to look after me. I went back to work for half a day a week. We confided in my secretary and she was brilliant when I was having a bad patch. I went into work and would be okay in the morning but by the afternoon I was too tired to drive home so my wife would come and get me. If I did not work the alternative was just sitting in a chair at home, but I would have gone barmy just sat in a chair. It took about 18 months until I started feeling a lot better.

22. HCV is awful. It overtakes you. You become depressed, it's debilitating and draining. I have a constant worry that my liver is being affected and I am developing cirrhosis. When I first started suffering from the HCV side effects I still had to go to the doctors for tests. I would lie in the car with the seats down and have a bucket to be sick in.

23. I currently have a medium damaged liver. My last Fibroscan in 2017 showed 7.9kPa which is fibrosis stage 1-2.

24. I first attempted to clear the HCV by taking Interferon and Ribavirin in November 2005. I immediately developed itching, sweats, fevers, abdominal cramps and intermittent palpitations. I had to abandon the treatment due to a severe reaction to the drugs.

25. A Fibroscan in 2013 then showed my liver was deteriorating and I had advanced fibrosis (13.4kPa) so I commenced treatment again on 4 January 2013 with Peglated Interferon and Ribavirin and it was successful. I did not know that my liver was starting to deteriorate before 2013. It just got worse and worse. I thought I was one point short of cirrhosis. My wife and I did not

know until very recently that the doctor thought I was not going to make it. He said *'you are one of our successes'*.

26. When I was going to start the treatment for a second time I had to have loads of meetings to see if I could handle it. They asked me a lot of questions to see if I could cope. They said if I suffered from any side effects they could help but that was not true. Dr Mervin Davies, the Hepatologist at Leeds said I had two choices, *'if you don't have it you won't survive, but if you do have it and it is successful you might live for another 25 years'*, he asked **GRO-B** if she could handle it. He was joking with us.
27. I did not face any difficulties in accessing treatment.
28. The treatment was horrendous. It involved taking tablets once a day and injections weekly for 9 weeks. The side effects from the treatment were awful. I suffered from constant tiredness before and after the HCV treatment. One of the problems was that when you stop the treatment the side effects do not stop straight away. It takes about a year for the drugs to clear from your system. It was a good year before I felt less tired and depressed.
29. I also had a rash and constant skin infections while I was on the treatment. I was fortunate a dermatologist prescribed all sorts of creams to try and help with my itchy skin. My skin was nearly raw at times. I still get lots of spots on my head and it is still itchy so I use E45 cream.
30. As a result of the second treatment I still suffer from impotence and this is a big issue for me. I have had appointments with doctors to explain my issue who said they could prescribe Viagra but the side effects of Viagra are horrific. I only have a little piece of liver left, so I am frightened to take any unnecessary medication. I don't want to tip the balance on my liver. I dare not take the chance. **GRO-B** said our marriage is not built on a love life like that. A lot of marriages would fail over something like this but **GRO-B** is very understanding.

31. There were also mental side effects from the treatment and I suffered with depression while I was on the treatment. I felt stressed because I worried that I would develop liver cancer. I have always been aware that because of my Haemophilia I may not live a long life, so I needed everything to be covered in case anything happened to me, but this was now coupled with the fact that my liver may fail at any time. It was hard to deal with. The psychological affect was frightening.
32. The treatment also affected my social life as I was not allowed to see anyone because I was so ill.
33. The second HCV treatment was meant to last for 24 weeks but I had to stop it early. During the treatment I had 3 blood tests that showed the HCV as zero, so I was hopeful that the treatment was working. Due to the side effects I really wanted to stop the treatment. I sat there wondering what to do. I told **GRO-B** I was stopping the treatment because I thought if I did not stop I would be dead in 24 weeks. I then told the doctors that I was sorry but I could not carry on. Luckily I still cleared the HCV even though I did not have the full course of treatment. The following year my Fibro scan results came down to 79kPA. It was amazing and the doctors could not understand it.
34. The doctor said under normal circumstances if they deal with a cancer patient and they are clear after 5 years they sign them off. There is justification to think the same applies with HCV. I will have one more Fibroscan and if nothing has changed, Dr Milson will consider signing me off. This would be a major step forward.
35. I have been very concerned about taking other treatments that I may need because it may impact my liver. I don't take any medication other than paracetamol because I'm worried. I saw a poster saying that at a certain age you should have a flu jab or shingles injection but the doctor said I was not allowed a live vaccination as it would go straight to the liver.

36. In August 1995 I was in a serious road traffic accident (RTA) and had to be flown to the Royal London Hospital. They knew I was HCV positive but they did not seem too bothered.
37. Due to the stigma attached with being HCV positive I kept my diagnosis a secret. Other than my children, my secretary, the [GRO-B] and [GRO-B] parents nobody knows. I was so worried that people would walk away and not shake my hand if they knew that I had HCV. People believe stories out of ignorance but it does not help you.
38. People would make fun of me when I went out because I could not drink. If I ordered a coke, people would laugh at me in the bar. I once asked if they did a non alcoholic wine and they laughed. Dr [GRO-B] told [GRO-B] that I was not allowed any alcohol for 2 years and I needed to have a low fat diet. It cost a fortune to have a low fat diet. It was so expensive to buy the right food which included a lot of fresh fish.
39. People knew I had Hepatitis because I was yellow. Even in more recent years, when I say I am a haemophiliac people ask about HCV and HIV. Once the Inquiry was in the media people understood more. That was the first time I felt I was able to tell people about my infected status.
40. My family were very supportive. My wife and I come as a pair, like book ends. My infected status did have an impact upon my wife because it affected her work as [GRO-B]. One of her colleagues knew I was infected so thought it was not suitable for my wife to continue working [GRO-B]. My wife was then tested for HCV and the results were negative so she carried on with her job.
41. I cannot get life insurance due to my infected status. I was concerned about [GRO-B] and the girls so I had to take out an over 50 plan. I have 3 of them which will cover my funeral costs. There is enough in there if anything happens to me. In most cases holiday insurance is denied as well or it costs a fortune. A one-week holiday had a premium of £350, which is more than the flights.

42. I was an [GRO-B]. I was shielded a little because I did not lose a salary but I had problems when I was running the business [GRO-B].
[GRO-B]

43. I retired when I was 62 years and I have a private pension with the company I worked for. It's not much of one though.

Section 6. Treatment/care/support

44. I don't think that I would benefit from counselling. I had counselling after the RTA and they asked about my childhood, but I couldn't remember it. I cannot remember anything from before [GRO-B] and I met as the RTA affected my memory.

45. My wife's friends, who were [GRO-B], provided me with all the mental support I needed. They were very good to me.

Section 7. Financial Assistance

46. I found out about the Skipton Fund through Dr Turner, who was a Haematologist at the Norfolk and Norwich Hospital.

47. In 2004 I received a £20,000 lump sum payment. In order to receive this money I had to sign a waiver stating that I would take no further claims against the NHS.

48. About two years ago we were on holiday and I was sat on the patio. I clicked on the news and Andy Burnham MP was talking about the Skipton Fund and the monthly pay-outs. I phoned the Haemophilia Society and asked about the monthly pay-outs as I was not receiving anything and I was told that I was entitled to another pay out.

49. I then rang the Skipton Fund, and they said they had been looking for me. I said '*looking for me? I'm not lost*'. I can see a letter in my medical records dated 21 November 2014 from the Norfolk and Norwich Hospital to N Fish at the Skipton Fund advising they could not confirm my new address in Yorkshire which I exhibit at WITN1049006, but the Skipton Fund had been sending me emails, so I do not understand how they could be '*looking for me*'.

50. The Skipton Fund agreed to back date the payments and I received a payment of £3,000 plus fuel allowance which I think took it to £3,500 a year. If I had not seen Andy Burnham and contacted the Skipton Fund, I believe they would have never have told me about the extra money I was entitled to.

51. When the Inquiry started the government sent me an email saying the payment had increased to £18,458 a year and all the extras that I could apply for before were all rolled in and I could not get top-ups. I was staggered, but we had no help when we needed it which was when I was ill and we had young children.

52. I object strongly to the money being means tested. They didn't means test me when they infected me HCV. I also object to them taking GRO-B's pension into account. I think that is very unfair.

Section 8. Other Issues

53. I believe it took the opening of a Public Inquiry to frighten the government into making a payment. They gave us HCV but they didn't give us help or money. People were left to do it on there own. I feel tremendously lucky that GRO-B has medical knowledge and we have such good friends who have provided me especially with support. Our GP has also been so good.

54. When we moved to Yorkshire in 2009 the Haemophilia Society asked me to go to my MP, so I met GRO-B MP in her surgery in around 2009 or 2010. She said that she was in the House when more money was announced

and the government had put £50,000 aside in case I got cirrhosis and I should be grateful. I said was not grateful. She lost her seat in the next election.

Anonymity, disclosure and redaction

55.I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry.

56.I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed:

GRO-B

Dated:

08-07-2019,

MEDICAL SUMMARY

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

- 1963 Summary of Treatment Card - Appendectomy
- 1976 Summary of Treatment Card - Wedge resection: toenail – plasma covered
- 1982 Summary of Treatment Card – Circumcision – FF Plasma / Factor VIII > Viral Hepatitis (Non A / Non B)
- 24/1/1980 Previously registered at Hull Haemophilia Centre. Now lives in **GRO-B**. Diagnosed at Lewisham aged about **GRO-B** after long investigations following bleeding after appendectomy at **GRO-B** Hospital. Other bleeding history – age 5 yrs. dental extract bled 3/5. Easy bruising all his life. xs bleeding after removal of It big toe 4 years ago – responded to FF... = mild FVIII deficit. Haemophilia A not FXI deficit
- Blood test. AST 16 iu/l (9-27)
- 25/1/1980 Hepatitis B screen test. HBs antigen negative
- 20/5/1982 Admitted 20/5/1982 for circumcision... operation 21/5/1982
- 7/6/1982 clinical notes. Jaundiced. ? Transfusion. Dr Black informed
- 14/6/1982 Blood test. Inf Hepatitis, repeat Thurs 17/6/82. AST 2018 IU/l (9-27), ALT 3435 IU/l (4-24)
- 15/6/1982 Letter Dr Black Consultant Haematologist to Dr Jack Darnborough, National Blood Transfusion Service. This patient had a circumcision on 21st May. We were told he had a Factor XI deficiency, diagnosed elsewhere, but we rediagnosed him as a haemophiliac with 38% Factor VIIC. The operation was covered with three packs of FFP (6176147, 6176133 and 6176173) plus one bottle of Armour Factor VIII concentrate contacting 490 units, batch number V52309. The following day he had a further 490 units of Armour concentrate, batch number V52309 and on the day after that two bottles of NHS concentrate each containing 240 units Factor VIII batch number HLA2928. He has now developed jaundice and the HBS result from our Microbiology Department is negative. His LFT results are as follows: bilirubin 144 umol/l, direct 100umol/l, alkaline phosphatase 306 IU/l, AST 2018 IU/l, ALT 3435 IU/l. Would you like any further information or blood samples?

ANONYMOUS

17/6/1982 (Dated 17/5/1982 in error) Letter Dr Black to Dr B Andrews Consultant Microbiologist. I enclose a copy of a letter which I have just written to Dr Darnborough notifying him of this patient with jaundice some two and a half weeks after receiving blood products. I would appreciate your comments on the possible ... use of this. It does not look like a hepatitis B and I wonder if it might be a non A non B, an A or even something unusual like CMV. Would you kindly advise me as to what investigations should be done, and liaise directly with his GP Dr GRO-B for the samples?

17/6/1982 Blood test. Second sample. More jaundiced but AST/ALT/LDU coming down. AST 1055 IU/l (9-27), ALT 2400 IU/l (4-24)

22/6/1982 Blood test. Jaundice & Liver function improving. AST 221 IU/l (9-27), ALT 934 IU/l (4-24)

29/6/1982 Blood test. AST 131 IU/l (9-27), ALT 388 IU/l (4-24)

6/7/1982 clinical notes. Clinically feeling better – but v depressed. Biochemically also significant improvement. Appt Fri week after LFTs. Still awaiting Non A/Non B result

6/8/1982 Blood test. AST 93 IU/l (9-27), ALT 186 IU/l (4-24)

17/8/1982 Feeling well again. Returned to work but increasing load gradually

16/9/1982 Microbiology Laboratory result. Hepatitis B screen. Hbs Antigen Negative

23/9/1982 Blood test. Reassurance. Significant improvement. Almost normal. AST 18 IU/l (9-27), ALT 82 IU/l (4-24). Repeat 1/12

3/12/1982 Blood test. Unsuitable Sample – due to late separation. Unavailable. Sample did not reach lab until 7/12/1982. Too late for AST & ALT to be done due to late separation.

1985 Summary of Treatment Card – HIV antibody status – Negative

14/2/1985 Microbiology – Hepatitis B surface antigen ... Negative, HBs antibody... Negative

3/9/1985 letter Dr Leslie, Consultant Haematologist to client. I thought you would like to know that your hepatitis and HTLV III tests proved negative

1987 Summary of Treatment Card – Haemarthrosis L Knee – I/V Factor VIII

11/8/1987 letter GP to Scottish Mutual. In 1982 he had a circumcision which was covered with three packs of FFP and Factor VIII concentrate. Following this transfusion he developed non A-B hepatitis. In February 1985 his HIV antibody status was found to be negative. As he has had no further transfusion this negative antibody status is likely to persist. This information has been supported by Dr A Black, Consultant Haematologist, Norfolk & Norwich Hospital

4/11/1987 Haemathrosis L knee after kneeling on it at the weekend. Given Factor VIII

7/11/1987 Re bleed into knee > A&E for further Factor VIII
Rx 840 iu Cutter F VIII conc iv given. Repeat tomorrow at 10am

8/11/1987 840 iu FCIII conc given iv

9/11/1987 720 iu FCIII conc given iv
Microbiology Hepatitis Bs antigen ... negative

10/11/1987 720 iu FCIII conc given iv
Violent reaction to F.....

11/11/1987 720 iu FCIII conc given iv

28/6/1989 5 d post arthroscopy R knee. Rx FVIII 1,000

23/4/1994 Microbiology Hepatitis C Abs detected. Confirmatory test result to follow
Hepatitis Bs antigen negative

27/6/1995 letter Dr Wendy Clarke, Staff Grade in Haematology Norfolk & Norwich to GP Dr **GRO-B**. I reviewed this **GRO-B** year old man in clinic today who has a Factor VIII level of 38% and a possible reduced Factor XI level. He has had several bleeding problems in the past requiring Factor VIII infusions and FFP and unfortunately had a severe episode of Hepatitis several years ago and has now been found to be Hepatitis C positive. I have briefly explained the consequences of this and will refer him to Dr Fellows for further management. I have also discussed the possibility of DDAVP infusions particularly subcutaneously at home and we will admit him as a day case for DDAVP trial in the near future. He has had no recent bleeding problems and has required no Factor VIII for quite a while now. We will review him routinely again in a years time

4/7/1995 Letter Dr Clarke to GP. I am writing to inform you that Mr **GRO-B**'s Factor XI level is normal with a percentage of 77 normal range being 60 to 200. He has also decided to decline from a DDAVP trial. His Factor VIII level is 46%

30/8/1995 RTA.

15/9/1995 30/8/1995 hit RTA by jack-knife lorry, rolled over

25/9/1995 Microbiology Laboratory result. Hepatitis Bs antigen not detected
Blood test. Globulin 36 G/L [21-35], GGT 138 U/L [0-60], AST 53 U/L [0-40], ALT 141 U/L [0-50]

20/12/1995 referral by GP to Dr Eleanor Arie District Rehabilitation centre, Colman Hospital for assessment following RTA August 1995 due to quite significant memory loss as a result of the accident

25/1/1996 There is mild increase in echogenicity of the liver, but with no significant attenuation of the bean.

26/1/1996 letter Dr Fellows to Dr Clark, Haematology. He was jaundiced about 12 years ago but has not been jaundiced since.

25/3/1996 Letter Mr Fellows to GP. This man with chronic hepatitis C and haemophilia is quite well. He is seeing Dr Kitson and the Trauma Counselling Service regarding the neurological effects of this RTA. I understand a court case is being brought against the other driver involved in June. He does not wish to pursue either liver biopsy or alpha interferon at least until that time

26/11/1996 letter Dr Clake to GP following annual review. I reviewed this 54 year old man who ... suffers with chronic Hepatitis C. He is under review by Dr Fellows for his chronic Hepatitis C which is stable at present and is undergoing no treatment for this

9/6/1997 letter Dr Fellows to GP. This man with Hepatitis C antibodies is quite well. He does not wish to contemplate treatment with Interferon, or a liver biopsy at this stage

27/11/1997 letter Dr Turner Consultant Haematologist to GP. Mr **GRO-B** remains unkeen on either a liver biopsy or Interferon therapy. I understand he has been vaccinated against hepatitis A and I think from what he and his wife said he has been screen for Hepatitis B but I would be grateful if you could check this for me.. Reviewing his notes he has never had a DDVAP trial but again

remains reluctant to consider this therapy in the meantime. I have therefore arranged to see him again in one year's time but have suggested that should he require any minor operative procedures or dental work then DDVAP would be the drug of choice

- 6/7/1999 letter Dr Fellow to GP. This man with hepatitis C and haemophilia is quite well. He drinks one unit of alcohol every two days... I discussed with him further the question of liver biopsy and possible treatment with Interferon and Ribavirin, but he does not wish to pursue this at present.. I have advised him to keep his alcohol intake to a minimum.
- 18/2/2000 excision of lesion upper lip (left) right side chin
- 15/9/2000 Blood test results ALT 209 U/L (0-50). Tumour Markers
- 20/9/2000 letter Jean Mackay, Clinical Practitioner in Gastroenterology to GP. He remains well and asymptomatic. He drinks three units of alcohol per week... We also discussed the question of liver biopsy, and he does not want to consider the procedure yet
- 18/6/2001 Microbiology Laboratory result. Hepatitis C RNA (PCR) Detected. HCV Type 3
- 30/6/2001 seen in clinic with wife. Long discussion re recent visit to gastroenterologists. Very worried re hep C, liver biopsy and future management
- 10/12/2001 Letter Dr MacKay to GP. He has decided not to have a liver biopsy and does not want further discussion on the subject
- 12/12/2001 Much calmer. Has joined Haemophilia Society. No planned surgery. No bleeding episodes
- 7/6/2002 Microbiology. Hepatitis C RNA (PCR) detected. HCV Type 3
- 6/12/2002 Microbiology. Hepatitis C RNA (PCR) detected
- 9/12/2002 Letter Dr MacKay to GP. On 28 Nov his gamma GT was 69, ALT 156, other LFTs, full blood count Us&Es and ESR normal
- 11/12/2002 No problems. No bleeding problems. No surgeries or dental work planned. Seen by IWF last week - "Hep C fine". LFT's normal. Review IWF 6/12
- 27/5/2004 Microbiology. Hepatitis C RNA (PCR) detected

ANONYMOUS

- 22/9/2004 letter Dr Turner to client. I enclose a letter for you along with some important patient information. I have been asked to send it to you by the Health Protection Agency
- 14/10/2004 letter Dr Turner Haematologist to GP. This patient has been identified as potentially at increased risk of CJD because he/she received UK derived plasma coagulation products between 1980 and 2001. It does not imply that he/she has received one of the plasma batches from a donor who has subsequently died from CJD
- 24/11/2004 Has read up side effects of pegylated IFN and Ribavirin. Very frightened by the side effects of Rx. Reluctant to undergo liver biopsy as no point if not going ahead with Rx. Has seen liver team – happy to wait until he decides. Feels extremely well so reluctant to consider disrupting lifestyle. No problems bleeding wise. Has had first payment from Skipton fund
- Letter Dr Fellows to GP. He decided not have a liver biopsy because he was very frightened about the procedure... I discussed with him again the indications for liver biopsy as the only way of determining whether he has scarring in his liver to indicate the need for anti-viral treatment. If he changes his mind, I will commission a liver biopsy.
- 28/11/2005 See last letter from Ian Fellows. Considering treatment without a biopsy. HCV RNA detected Oct 2005. Tried treatment – 8 tablets and 1 injection. Reacted: temperature, joint pains and urinary retention. Will be seen by liver team sooner than expected. Happy to accept recombinant factor VIII. GET
- 21/10/2005 contacted by wife to discuss biopsy / treatment – pt would like treatment without bx. Discussed treatment side effects + monitoring. Drinking very little alcohol (1 glass wine/week)
- 24/10/2005 Microbiology. HCV RNA detected. 2,846,476 HCV RAN iu/ml
- 21/11/2005 Injection technique shown. To start today
- 23/11/2005 wife phoned – tachycardic, fever 38°, abdomen cramps, itching, headaches. Come to GUIST
- Just started tmt for Hep C. c/o itching, sweats, fevers, abdo cramps also c/o intermittent palpitations fast & irregular. Wants to stop treatment. Pt stopped antiviral treatment at this visit

28/11/2005 improved. Still some slight itching. Occ headache

23/2/2006 Ultrasound abdomen. The liver is of diffusely increased echogenicity consistent with fatty infiltration. Normal hepatic venous and portal venous traces were obtained.

20/4/2006 letter Dr Fellows to GP. This man with chronic hepatitis C type 3 and haemophilia had a profound adverse reaction to pegylated Interferon and Ribavirin. He had to stop the treatment after one injection and eight tablets. He is now well ... He has not drunk any alcohol in the last five months... There is no other anti-viral treatment to offer at present

6/10/2006 clinical notes. Advice not to drink alcohol

Letter Dr Shaukat, Specialist Registrar to Dr Fellows to GP. As you know he had a severe reaction possibly due to the treatment. At the moment he feels well in himself and is quite happy that he is not on any treatment. His last ultrasound was February which showed fatty liver only. His latest LFT's showed no worsening of his ALT. I am happy to sit and wait.

8/5/2007 letter Dr Fellows to GP. This man with haemophilia and type 3 chronic hepatitis C infection is well. He does not take any medication, and does not drink alcohol... His last LFTs in October last year showed ALT 133, with otherwise normal value... He was intolerant of anti-viral therapy

28/6/2007 Ultrasound abdomen. Indication: Hepatitis C, haemophiliac. ALT 133, other LFTs normal. The liver, as previously noted, appears diffusely echo bright, suggesting fatty infiltration. No focal lesions seen within the liver. Normal hepato pedal flow shown in the portal veins. No ascites or recannalisation of veins seen.

30/10/2007 consent to take part in the teaching of medical students by adult patient

12/6/2008 ultrasound abdomen. The liver appeared normal in size and texture, with no obvious focal lesions

22/4/2009 letter Dr Fellows to GP. His last blood tests in November last year showed an elevation of ALT at 447 and gamma GT of 156 but his bilirubin was normal

22/6/2009 Ultrasound abdomen. The liver is of normal echo texture with no focal mass lesion identified

2013 Fibroscan pre treatment 13.4kPa

2013 HCV treated (Pegylated Interferon/Ribavirin)

20/10/2015 Letter Dr Milson to GP. [GRO-B] did mention that he is getting some erectile impotence and this was almost certainly precipitated around the time of treatment for his Hep C

2017 Fibroscan 7.9kPa (Fibrosis 1-2)

9/7/2018 Letter Dawn Orange (Specialist Nurse Hepatology) to GP. Prior to his treatment in 2013, a Fibroscan reading indicated advanced fibrosis. He has been followed up on our Cirrhosis Surveillance Pathway, however the most recent of his Fibroscan in 2017 indicated a median liver stiffness of 7.9kPa which translates as fibrosis stage 1-2 (according to the Metavir score) and this is correlated with blood tests taken regularly, which are non-concerning and an ultrasound scan of his abdomen which is reported as normal