

Witness Name: John J Lister

Statement No:WITN1350001

Exhibits:0

Dated: November 2018

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JOHN JAMES LISTER

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I, John James Lister of GRO-C will  
say as follows:-

#### Section 1: Introduction

1. My name is John James Lister, date of birth GRO-C 1949. I was born in Lancaster and now live in Bournemouth.
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. From an early age it was evident that I had inherited haemophilia from my grandfather. Little was known about the blood disorder in those days and there was no treatment available. When I was quite young I had a test at the Lancaster Infirmary where my ear was pricked and the blood was dripped

onto blotting paper. This was the only test for haemophilia at the time and, as my blood clotted in the air, I was told I did not have haemophilia.

4. To describe my childhood as difficult would be an understatement. I was in constant and considerable pain and spent a lot of time in hospital. At the age of 4 or 5 I was bedridden for many months with a leg problem that the doctors could not diagnose. I had to learn to walk again after this episode.
5. My family moved to Bournemouth when I was about 12. My condition didn't improve. I found it very hard to make friends at school as I was absent so often with what I now know were various bleeds.
6. I was a very keen footballer and was talented enough to be selected for the town youth team. It was here that I was scouted by Bournemouth FC. I signed the professional forms on my 17<sup>th</sup> birthday. I was so proud to have overcome some difficult times and felt optimistic about my future.
7. After a few weeks of playing I sustained a dislocated patella and was sent home to recover. However, after a week of indescribable pain I was taken back into hospital. I was suffering from internal bleeding and my knee had swollen to 3 times its normal size. I had to have blood drawn from my knee with a huge needle.
8. It was then (in or about 1966) that I was seen by Dr David Stern, a pioneering haematologist and he told me that I did in fact have moderate haemophilia, something that I had already suspected. I suffer from Haemophilia A. He told me that treatment was now available in the form of Cryoprecipitate which would replace the defective gene and stop the pain. My primary feeling was one of complete relief that I now had both a diagnosis and an answer to my illness. I felt very optimistic.
9. Dr Stern became an important person in my life because he encouraged me to continue to play football. He said it would help build out my muscle and resist bleeds, and really encouraged me to live a normal life. I saw him on a regular basis (when I sustained an injury). It was however a great sadness that I was unable to continue to play professional football – haemophilia and

competitive sport were simply not compatible even with the advances in treatment, and I left Bournemouth FC when my 1 year contract expired.

10. During my 20s Factor VIII became available. This was a major step in the treatment of haemophilia.
11. At some point in the 1970s I had a very bad reaction to treatment with Factor VIII which caused me to shake violently for about 30 minutes. On another occasion I developed large red blotches all over my body. On both occasions I went to see Dr Stern and he gave me an antihistamine tablet. He said "it's just the impurities in the blood". I trusted Dr Stern and did not dwell on it too much. I simply accepted the advice of the medical professional who was treating me and had been treating me for about 10 years.
12. I have been unable to find any reference to these adverse reactions to Factor VIII in the medical records that have been provided to date.
13. A few weeks after the second reaction to Factor VIII I began to feel something was very wrong. I was exhausted all the time and, despite being a fit young man, I felt the fatigue of a man very much older. After several visits to the GP they commented that my symptoms were very much like a type of Hepatitis although blood tests didn't confirm this. I now know that Hepatitis C was not widely known at that time and that there was no test available to diagnose it.
14. I continued to receive Factor VIII after this because I had a poor response to DDAVP.
15. I was never given any advice or warning that there was a risk that the blood products I was given could be infected. I was never advised that there were any risks associated with Factor VIII which was dubbed the new wonder drug for haemophiliacs.
16. I have never been told when I contracted Hepatitis C (Genotype 1) but, having seen my medical records, it is clear that I first began to complain of multiple

health issues shortly after treatment for a bleed in late 1975 for which I was treated with Factor VIII.

17. For the next 30 years I felt the fatigue daily but was told it was just a symptom of my thin blood and haemophilia. In the mid 1990s I saw a television programme about hepatitis C and the links to haemophilia. I approached my haematologist (who by then was Dr Alison Worsley at Bournemouth) as I suspected this could be the reason for my fatigue. She initially told me that I did not have it, but when she checked my notes she discovered that I had actually contracted Hepatitis C. If I had not contacted her and specifically asked about Hepatitis C, I would not have been told about the infection at all.
18. It is clear from my medical records that my treating doctors knew I was Hepatitis C positive in 1990. There is reference to this in correspondence although there are no test results contained in my records which match this date. As stated previously, my records appear to be incomplete.
19. Dr Worsley described it as being nothing to worry about – she said it was just like a stomach bug you would get on holiday. She told me that the media had blown the issue out of proportion and accused them of 'scaremongering'. Even after all the years of pain and fatigue it was still being written off as nothing serious. I maintained my trust in the medical professionals treating me despite this.
20. Even after this date, I was given no real information regarding the disease. I was given no warning from doctors as to the potential transmission of the virus and was explicitly told by Dr Worsley that there were no known cases of Hepatitis C being transmitted through sexual intercourse, and is only really a risk for drug users who share needles.
21. It was some years later when I realised the severity of my condition. It became apparent that medical professionals knew of my condition for many years but had not informed me. They not only put my life at risk but that of my wife and my daughter who was born after I contracted the disease. I was denied the chance to take steps to protect my family. If I had been made

aware of the disease when it was initially tested for or diagnosed, or at least informed of the severity of the disease afterwards, I would have also had the opportunity to take preventative steps to protect my liver.

22. There are more than 10 years of medical records missing from my hospital notes. There is almost nothing in the records I have been given from 1977 until 1990 when my records refer to me being a "known" case of Hepatitis C.

### **Section 3: Other Infections**

23. I was also exposed to HIV. I cannot recall being advised about being tested for HIV in 1985 and 2004 but accept that I probably was given the content of my medical records.

### **Section 4: Consent**

24. I had never consented or been told that I had been tested for Hepatitis C until my discussion with Dr Worsley when I was diagnosed.

### **Section 5: Impact**

25. Despite my daily fatigue I tried to live my life as best I could and do the best I could to look after my family. I married at 19 and had 3 children. I started my own wholesale greengrocer business in the early 1970's and became quite successful locally. I was able to buy a house and eventually move up the property ladder; my family and I moved to a larger house in 1990.
26. However, as I became older it got harder to get through each day. I was in so much pain and the fatigue was progressively harder and harder to overcome. My business began to suffer, I just wasn't able to put in the hours anymore and going to the markets in London everyday became too physically demanding. I couldn't afford to keep on the staff and I couldn't get out to work myself. Slowly I was losing everything – first my business (which at one point was turning over £250k a year) then my home.

27. My business went into liquidation in or about 1992. We were unable to pay the mortgage because I could not work and eventually the family home was repossessed. I was left with no option than to claim benefits which I found shameful as someone who was a hard worker and had recently owned a successful business.
28. We were allocated social housing but this was not something I could cope with. I had worked all my life to be left with nothing. I couldn't face the pain and the shame and felt an overwhelming cloud of depression. I attempted suicide in 1992. I am not proud of this. I took an overdose of aspirin and bled into my stomach. I very nearly succeeded in my attempt but was saved by Royal Bournemouth Hospital. Following this attempt I felt very isolated from my family. I couldn't face each day and I wouldn't let anyone in. I couldn't imagine that anyone could understand how I was feeling.
29. My marriage was suffering and my wife and I had been separated for many years before our divorce in 2017. I felt very isolated from my family and I was unable to provide for my children how I wanted to. My grandchildren have also been unable to have the grandad I'd have loved to be as my illness meant I could not be as active in their lives.
30. Whilst it is impossible to blame all of the hardship in my life on my infection of Hepatitis C, it has certainly played a large part. My fatigue and inability to work was the catalyst for the demise of my business, and subsequent loss of my home and family.
31. I was very aware of the stigma attached to Hepatitis C, and I would refrain from telling people other than my family and close friends. I recall on one occasion I paid for a massage, and I said that I suffered from Hepatitis C on the form I was filling out before. Upon seeing this, the masseuse refused to massage me.
32. I also felt this reaction from those in the medical profession, who often seemed extremely cautious around me. They would be very nervous when taking my blood and I knew that they treated me differently. I believe that I

was tarred with the same brush as those who were infected with Hepatitis C through drug use.

33. There is no doubt in my mind that there was a cover up. Those treating me had known for years that I was infected with Hepatitis C but I was not told. By then it was too late for me but I could have taken steps to protect my family. This opportunity was taken away from me. The cover up is unforgivable. It is as if people's lives just weren't important.

34. When I ordered copies of my medical notes around 2010, I noticed that large sections were missing and it all began to fall into place and I realised the extent of the scandal. More and more information was becoming available through media outlets and, later on, social media. It was apparent that I was not alone in my suffering and there were thousands more in the same or similar situations.

35. I have been referred to as one of the "lucky ones" as I only contracted Hepatitis C and I am still alive. I don't feel lucky. No one touched by this scandal feels lucky and these sorts of trite comments simply compound the problem – people are dying but it's ok because "it could be a lot worse". How much worse does my life need to be? Do I need to die before my story is taken seriously as thousands of others have already done?

36. It is hard not to attribute blame. I don't blame Dr Stern or the other NHS professionals. They did the best they could with what was at their disposal. They were however complicit in the cover up that followed. People were aware of this and didn't tell us. They risked the lives of innocent people. I am still so angry at the pharmaceutical companies and the government who continued to use contaminated blood products.

37. I believe that haemophiliacs were used as guinea pigs with a view to discovering more about these blood borne viruses. It is totally unforgivable.

38. The suffering and hardship, not to mention the social stigma attached to the Hepatitis C virus that so many haemophiliacs and their families endured both during the time of diagnosis and afterwards. And that doesn't even take into

account the 2,400 and rising who have died as a result of this scandal. It is unbelievable.

39. I am angry and bitter and feel cheated out of a pretty good life that I had built for myself and my family. I worked so hard. I played down how bad I was feeling so as not to trouble them and it was all for nothing because I still lost it all.

40. I now live in a one bedroom flat with second hand furniture.

#### **Section 6: Treatment/Care/Support**

41. In 2007 I started 48 weeks of treatment for Hepatitis C with Interferon and Ribavirin. The interferon made me extremely unwell. I would have violent migraines where I would be unable to take my head off of my pillow, and I had lost so much weight that my clothes were falling off me. I also suffered from fatigue and general malaise. I was in such a bad way that my friends and family thought I was going to die. On one particularly bad day, my wife took me to the hospital but they only gave me paracetamol. After 3 months of treatment, the doctors advised me to stop as I would not have survived another 15 months like that. I followed their advice and stopped the treatment, from which it took me months to recover. This experience was mentally scarring and don't feel like I will ever fully recover from this; the toll on my mind and body has been irreversible.

42. I was not offered any counselling or support at this time (or at the time of my diagnosis). I believe would have particularly beneficial to me at the time of my treatment as I was so scared at the time. This was not helped by one of the nurses at the hospital who told me she did not understand the treatment, before giving me the drugs to be self administered at home.

43. After this, I found out about the new treatments available through the Hepatitis C Trust. I then went to a meeting in London with the Haemophilia Society where I received more information regarding the new treatments available.



44. I had to fight to be considered for this new treatment because I was told I was too old, but was eventually given Harvoni when I was in my 60s – after 30 years of suffering. This treatment was a 12 week course of tablets with very little side effects, which successfully cleared the virus.
45. I suffered from stage 3 fibrosis before this treatment and I was very close to suffering from cirrhosis, however following the clearing of the virus my liver is now improving. I now also have much more energy than I did when suffering from Hepatitis C.

### **Section 7: Financial Assistance**

46. In 1994 I was made aware by the Haemophilia Society that I may be eligible for a £20,000 payment from the Skipton Fund. This was given as a one off payment and I had to sign a waiver to confirm as such, but I was on benefits at the time and in dire straits so had no other option than to take the money.
47. I have received a payment from the Caxton foundation for £12,000 to pay off a loan, I was made to feel like I was going to them cap in hand, begging for it.
48. I was also involved with the litigation in America in or about 1991, despite the advice of Dr Worsley not to get involved with it. This litigation ended with a payment of \$7000 but there was no admission of guilt. I was asked to sign a waiver when I agreed to the settlement to confirm that I would not take any future action.
49. I was previously on Disability Living Allowance but after that was amended, I had to go through 2 appeals and a tribunal to receive Personal Independence Payments last July. Initially I was assessed as able to deal with things despite the brain fog that I complained of and which I was finding debilitating.

50. I now also receive payments through EIBSS of £1500 a month. I believe I only received these payments because of the help given by my treating doctor, Dr Mainwaring. These payments are making a big difference to me.

51. I have heard people say that haemophiliacs are just after a pay-out. This is incredibly heartless and hurtful after all we have been through. We deserve restitution; we deserve to have back all we have lost.

52. We will never have our health back, or the people back who we have lost but we deserve to know the truth about why this happened and who exactly was involved in the cover up. I hope that this Inquiry will bring us all the answers we have waiting decades for.

**Anonymity, Disclosure and Redaction**

53. 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.

54. I do not want to be called to provide oral evidence.

**Statement of Truth**

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

Signed. GRO-C.....

Dated 09/11/2018

### MEDICAL SUMMARY

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

1966            Diagnosed with haemophilia (age 17).

26.11.1967    Football injury to L knee.. Frozen plasma transfusion 1 litre.

10.02.1969    Football injury into anterior chamber of L eye,. Cryo 100 cc. Cryo 90 cc.

06.08.1969    L shoulder. Cryo 60 cc.

01.04.1970    R thigh haematoma. Cryo 72.

13.01.1971    Haematoma of R vastus laterals. Cryo given. 73 kg.

26.08.1972    13 bags cryoprecipitate.

16.03.1975    RTA. Given cryoprecipitate. 14 bags.

25.09.1975    Had another transfusion mid-day today. Arm injury.

24.11.1975    Knee injury treated with Factor VIII (5,400 units).

26.11.1975    5,4000 u Factor VIII transfused.

29.03.1976    Hospital records. Patient known haemophiliac since age of 17 and has had bleeding trouble in the joints and muscles from time to time and treated accordingly (under care of Dr Stern). He has had no trouble for last 4 months. During the last 1 year has been feeling run down,

generally felt tired and sleepy at the end of the day. Has been slowly losing weight.

- 10.01.1977 Hospital records. Refers to mild haemophilia being diagnosed at 17.
- 29.06.1977 Letter from Consultant Haematologist to Dental Surgeon. I will happy to transfuse Mr Lister immediately before you do your restoration work.
- 08.05.1982 Hospital records. Seen in casualty, punched in face. Check HIV status. 1000 u F VIII.
- 15.10.1985 Letter from D G Oscier to patient. I am very pleased to tell you that your AIDS antibody test was negative.
- 26.05.1990 Injured at work. Given 4 x 285 FVIII..
- 05.09.1990 Letter from Dr Worsley to Consultant Orthopaedic Surgeon. With mild haemophilia he is rarely seen here though he has one fall and injury to the left hip which required Factor VIII treatment in May of this year. In 1977 he has persistent bleeding from a tooth socket which was slow to respond to Factor VIII treatment and he was found to have an inhibitor. The bleeding resolved using large doses of Factor VIII. Later on that year he banged his right elbow and again needed large volumes of Factor VIII.
- 19.09.1990 Annual review sheet. Hep C positive.  
**This sheet is incomplete (there is a PTO reference and no second page).**
- 07.03.1991 Letter from Dr Worsley to GP. Previously Mr Lister was working very hard in his wholesale fruit and veg business which meant lifting a lot of heavy crates about and this led to several minor bleeds. Lately due to the recession he has not had to do as much hands on work and is

enjoying the less stressful life style. Certainly he seems much more relaxed and cheerful and less physically tired.

- 16.03.1991 Regular review sheet. Hb S ab position: needs no vaccination. Hepatitis C positive.
- 13.04.1992 Letter from Psychiatrist to GP. Saw Mr Lister at hospital on 13<sup>th</sup> April 1992 following an overdose last week....He took the overdose because he was feeling low and depressed. He admitted that he had lots of financial problems and also marital and domestic problems. He had his own fruit and vegetable business for the last 15 years but due to the recent recession he has had lots of difficulties and he is unemployed now. He also has lots of debts, round about £30,000 and he might lose the house. His house is now on a suspended repossession order. Following all these difficulties he started to feel low, depressed with poor self image and low self-esteem. He says he has been depressed for the last 2-3 months and he started to drink heavily. He has been married for the last 23 years and has three children, two daughters and one son, and two grandsons....When he took the overdose he left a note, but he says he did not want to kill himself. When he took the tablets he started to think about his children and stated to feel panicky and he presented himself to the hospital. When I saw him today he was more relaxed, not severely depressed and not suicidal. No evidence of any psychotic features. He acknowledged that the main problem is his financial and domestic problems.....no immediate risk.
- 16.04.1992 Letter from M Williams (haematology) to GP. Admitted on 6<sup>th</sup> April following an Aspirin overdose. He presented on that date having taken between 40 and 60 Aspirins as well as two pints of lager and though initially well by that evening had started vomited frank fresh blood and began passing large quantities of melaena....Given extremely large doses of Factor VIII in order to keep his levels above 60%.....In addition the psychiatrists here are arranging follow up from their point of view.

His mental state however was markedly improved by the time he was discharged and he certainly did not seem actively suicidal.

06.05.1992 Annual review sheet. Investigations:

Hep B ab – pos – previous infection

HIV ab – previously neg

Hep C ab – known pos

27.05.1992 Letter from Dr Worsley to GP. Review following complications of Aspirin overdose with GI bleed and pneumonia....Since he was given large amounts of factor VIII while in hospital he will need a further follow up in 6 months time for checking of the HIV antibodies and liver function tests.

13.08.1992 Letter from Dr Worsley to Bournemouth County Court. I am writing to you to request a delay on the repossession order which is to be made on his property.....He has worked extremely hard keeping up his fruiter's business. Earlier this year he suffered a period of severe ill health including gastro-intestinal bleeding complicated by pneumonia which required some weeks in hospital. I understand that at this time his business was already struggling and his financial problems were becoming greater. The illness then made him unable to work and to arrange his affairs and precipitated the situation you are now discussing. I would hope that eventually he would regain his physical health and thus be able to do a full time job again.

14.08.1992 Letter from Dr Worsley to patient. We had a telephone call from the Haemophilia Society yesterday to day that they will pay your outstanding Gas Bill apparently about £445.00 so that you will be able to put the gas on in the next place that you move to.

1993 Diagnosed with factor VIII inhibitor.

- 29.04.1993 Letter from Dr Worsley to Housing Benefit Department. His health was in general good and he was able to keep down quite and active job as a greengrocer until the middle of last year when the business began to fail. Mr Lister became depressed and over-worked and ended up in hospital with (a) pneumonia and (b) gastro-intestinal bleeding for which he required several weeks of treatment....He has physically and emotionally deteriorated particularly because of last years hospitalisation and I think that the trauma of having to move house at the moment would be extremely detrimental.
- 22.07.1993 Hospital records. Serology done for HAV, HBV, HCV and HIV. Counselling later.
- 09.12.1993 Letter from Dr Worsley to dentist. He has developed a very nasty antibody to factor VIII as a result of the several infusions of factor VIII he was given in the summer to cover dental work.....Had several bled since which have responded to large doses of factor VIII but the inhibitor remains such a problem that I cannot see us being able to offer suitable cover for safe dental work.
- 09.12.1993 Letter from Dr Worsley to Rheumatologist. Mild haemophiliac but acquired antibody to factor VIII...For many years he has run a successful fruit and vegetable shop, though this has recently gone under with recession.
- 06.02.1994 Hospital record. Self referral. Vomiting. Inhibitor developed in 1976 but not detected May 92. Reappeared July 1993 (2 B.U on 15.10.93). HIV neg July 1993. Hep C Pos. Hep B Pos (sAg).
- 17.02.1994 Letter from G Short to GP. Refers to Hep C positive July 90.
- 29.04.1994 RA for Dental Surgery. Known Haemophilia A at age 17. Mild problem until last 3 years. Developed an inhibitor. Until last 3 years v. rarely needed Factor VIII. Repeated problems last 3 years because of

spontaneous bleeds (1-2/52). HIV negative July 1993. Hep C +ve.  
Hep B +ve.

- 25.07.1994 Letter from GP. He is married and is currently in the process of applying for council accommodation.
- 24.11.1994 Hospital record. Advise for admission for dental work. Due for theatre about 3 pm on 29.11 – give 8Y at 2 pm. Please given 3000 u Factor VIII – “8Y” 1 hr before procedure.
- 18.01.1995 Clinic records. Came up for extra visit as was worried about a TV programme about Hepatitis C (is Hep C ab pos, LFTs N in 1990 and 1992 but have not been monitored regularly). Reassured, given Haemophilia Society “Hepatitis” booklet – offered to test spouse. For regular LFT monitoring – due to be seen in May anyway.
- 25.09.1996 Clinic records. Came up “out of the blue” for h/w green card. Discussed Hep C again. Not keen to have regular monitoring, Hep C viral typing or liver specialist opinion. Given latest Hep C literature.
- 09.07.1997 Letter from Dr Worsley to GP. I do not see Mr Lister for a regular routine since he has just mild haemophilia, so is not really expected to have any bleeding problems unless he has elective surgery. The last time he needed to be given factor VIII was in 1994 to cover some tooth extractions.....came to see me last month out of the blue to fill in a DLA form and I took the opportunity to check his liver function tests.....Slight raised ALT...but quite raised gamma GT.....He is known to be hepatitis C positive but is not keen to have a specialist liver opinion or Interferon treatment at the moment.
- 21.01.1998 Letter from Dr Worsley to GP. He returned over the Christmas holidays and I sent blood off for molecular testing for the hepatitis C viral RNA and I have just received the results, which shows that it was detected so as expected he has significant hepatitis C involvement.



- 21.01.1998 Letter from Dr Worsley to patient. I have the results of your genetic test for the hepatitis C, which does show that hepatitis C viral RNA is detectable in your blood. Since, as you know, your recent liver function tests showed very little change.....I think all we need to do for the moment is to follow the levels....
- 17.06.1998 Letter from Dr Worsley to Dr Winwood. He had been exposed many times to Factor VIII concentrate in the past and presumably because of this was found to be hepatitis C antibody positive when I screened all the patients in 1990. He had normal liver function tests in 1990 and 1992 but I had not monitored these regularly until about 1995. An autoimmune screen done in 1994 was negative.....Up to now he has been well and fit, although he has not been working since he got into financial trouble and lost his business of fruit and vegetable shop four or five years ago....In December 97, I sent blood for hepatitis C viral load, this went via the Virology Department rather than to our Haemophilia Service at Edinburgh, so I just got the report that of "hepatitis C RNA detected by PCR test" On talking things over at his latest review appointment today he would like to have some more expert information and evaluation of his liver, and I have mentioned the possibility of Interferon or combined anti-viral therapy. However, in the past he has had a history of depressive disease including one attempted Aspirin overdose so you may not feel him a candidate for such therapy.
- 08.07.1998 Letter from Dr Worsley to GP. He has been well during the last six months, but complained that he is tired all the time.....He is bored and would like to work but is caught in the Social Security poverty trap. He has now moved to a Housing Association house in Wolverton road. On discussing the hepatitis C he felt that he would now like to be evaluated by a hepatologist and I have referred him to Paul Winwood.
- 29.10.1998 Letter from Dr Winwood (gastroenterologist) to Dr Worsley. He had multiple transfusions of factor VIII in the 1970s which is almost certainly

the source of his hepatitis C. I note that he is both antibody and PCR positive. Liver functions tests have previously been normal but over the last 2 years his ALT has fluctuated between 50 and 62 and his gamma GT has been raised....He admits to drinking 28 units of alcohol a week which is a little on the low side to account for his LFTs although he may not be being completely honest with me. In himself he feels well although he tires easily. There are no symptoms to suggest hepatic decompensation. I note that his past history includes depression and an overdose in Aspirin in 1992. He says that this was secondary to his business going bankrupt at the concomitant loss of his house etc. The psychiatric assessment in the notes is consistent with this suggesting that he does not have innate depression. As you say, however, this could be a concern were we to treat him with Interferon. No signs of chronic liver disease and no abnormal findings.....from the information he has been given has decided that he does not want Interferon at present. I think this is reasonable although I would offer him treatment if he so wanted it....In terms of further management it would be worth keeping him under review for when less toxic treatments become available.

25.04.2000 Letter from Dr Winwood to GP. He did have some malaise recently but this has resolved....He still does not want to be considered for any anti-viral therapy and I have offered him the opportunity to go to Southampton for a biopsy with Factor VIII cover. He has declined this.

11.04.2001 Letter from Dr Buttifled (gastroenterologist) to GP. He says that he has been increasingly listless, over the 6 months and feeling generally fatigued. He has had a loss of appetite but no weight loss, occasionally he feels low in mood and tearful. His libido has decreased over the last 12 months and he has trouble dropping off to sleep necessitating an occasional use of Zopiclone. He is still not keen on receiving anti-viral treatment or having a liver biopsy at Southampton with factor 8 cover. He has also discussed antidepressants with yourself and reiterates that he is still not keen to take any form of

medication in case he becomes reliant....He is happy to develop a watch and wait policy on his hepatitis C.

- 15.01.2003 Letter from Dr Worsley to GP. He was worried about being generally unwell for the last six months. He feels that he has been catching lots of colds and he has two chest infections....He seems to have been a bit lost to follow up as far as the Hepatitis C goes and I will get in touch with the CNHS in Hepatitis C to get him seen again. He puts most of his symptoms down to possible Hepatitis C effects. He has a little bit of weight loss. He suffers from intermittent mild depression and on some days he is tired and not able to do much. At other times he is as well as usual and able to help his sons with, for example, building work in restoring houses.....He does admit to continuing to drink probably too much since, he really with the hepatitis C, should be sticking to less than 21 units a week.....
- 28.01.2003 Letter from Dr Worsley to patient. Blood results show the Factor VIII inhibitor screen remains negative. LFT remains slightly abnormal but similar to those taken in April 2000, so are stable but interestingly your blood count is not quite right – the haemoglobin level is raised. This means that your blood is a sticky and we call this condition polycythaemia.
- 10.02.2003 Clinic records. Discussed prognosis, alcohol intake, risk of transmission. Still not keen to have any anti viral therapy.
- 27.02.2003 Letter from CNS to Dr Worsley. We had a general chat today about hepatitis C and we discussed prognosis and the risk of transference. We also discussed the possibility of him having a course of antiviral therapy, but he still prefers to be monitored and is not keen to embark on treatment at present.....I have reassured Mr Lister, as far as possible, that there are no signs of severe liver damage, or that his liver is struggling at this point. Obviously we are unable to give him a definitive answer on prognosis without being able to undertake a liver

biopsy, as you know it is not part of our protocol to do biopsies on haemophiliacs for hepatitis C in this area. I have suggested that if he was particularly keen to know how his liver was, then we could arrange for him to have a biopsy in Southampton. He is happy not to have this done.

16.02.2004 Clinic records. Feeling generally unwell over past year. Fatigued and general malaise. Can also feel low emotionally, headaches. ...Discussed possibility of having anti viral therapy but he is not keen and would like to be monitored at present.

23.02.2004 Letter from CNS to Dr Worsley. John tells me that he has been feeling generally unwell over the past year with fatigue, general malaise, feeling emotionally low and headaches. He has also been experiencing a rash on his buttocks, which has been a problem over the last 6-7 months. It was suggested to him when he saw a locum GP that the rash is common the patients who are HIV positive. I am aware that you quite often screen your haemophiliacs for HIV and I was wondered when John was screen last and whether you feel it would be advisable to get this re-checked. However, John tells me that he has not had factor 8 for about 7 years and does not appear to have any other recent risk factors for HIV.....We discussed the possibility of him going on to some Anti-Viral therapy for his chronic Hepatitis C but he is not keen to consider this at present.

15.09.2004 Antibodies to HIV not detected

14.02.2005 Clinic notes. Does have period where he gets a run down physically and very fatigued. May be associated with his chronic HCV. Discussed AVT, not keen on having treatment, would rather be monitored.

13.04.2005 Normal liver scan.

- 31.10.2005 Clinical records. Genotype 1b. Liver ultrasound = normal. Symptoms fatigue, poor energy levels, low emotionally.
- 08.05.2006 Clinic records. Discussed treatment. Would like to be monitored at present and will think it over..
- 12.05.2006 Letter from CNS to GP. John tells me that he is generally well, although, he does experience periods of fatigue. He has cut down on his alcohol intake...I have encouraged him to keep his alcohol intake to a minimum. We discussed again the possibility of him commencing a course of antiviral therapy with PEGylated Interferon and Ribavirin. He tells me that he has been thinking it over, but generally he is not keen on treatment. He would like to continue to be monitored so that he can consider treatment further.....If he changes his mind with regards to treatment he has only got to contact me and I can put him on the waiting list.
- 02.10.2006 Letter from Dr Mainwaring to GP. His mild haemophilia A is not a problem bearing in mind his lack of bleeds.....He doesn't appear to have any significant problems with his chronic hepatitis C and is still considering the question of treatment with regulated Interferon plus Ribavirin.
- 06.11.2006 Normal liver scan.
- 23.12.2006 Oncology clinic record refers to PMH – Hepatitis C type 1B.
- 01.03.2007 Clinic records. Not wanting treatment at present.
- 06.03.2007 Letter from CNS to GP. Patient is well at present....normal liver function apart from an ALT of 47.....An ultrasound scan of the liver in October showed a liver of normal size, contour and echogenicity. The spleen was also normal and there was normal directional flow through the portal vein.....We discussed again the possibility of him going on to

a course of antiviral therapy with PEGylated Interferon and Ribavirin. However, he continues to be reluctant to have treatment mainly because he is genotype 1 and would require a years treatment with only around a 48% chance of gaining a sustained virological response.

26.04.2007 Letter to GP following clinic appointment with Dr Mainwaring. Patient wanted to discuss things following the reporting of the ongoing hepatitis C enquiry. Mr Lister now wonders whether his abdominal pains, fatigue and other problems relate to hepatitis C infection. I said this is a definite possibility.

26.04.2007 Letter from Dr Mainwaring to CNS. Mr Lister would now like to reconsider therapy for his hepatitis C infection in view of the problems he is experiencing with on and off abdominal pain.

14.05.2007 Hepatitis C RNA detected by PCR

14.05.2007 Clinic notes. Recently started antidepressants. Fatigue, malaise, low mood, IBS symptoms since appointment in March. Would like to start anti viral treatment in Sept.

22.05.2007 Letter from CNS to Dr Mainwaring (treating specialist). He has genotype 1, chronic hepatitis C. He has now decided that he would like to go forward for some antiviral treatment in an attempt to eradicate the infection.....He has felt generally unwell...troubled with symptoms of fatigue, malaise, low mood and has also been having problems with IBS type symptoms. He recently commenced an antidepressant....Because he is genotype 1, he will need a 48 week course of PEGylated Interferon and Ribavirin and has around a 50% change of gaining a sustained virological response.

01.12.2009 Letter from Bournemouth Hospital to GP. Results of recent liver scan reassuring. No change in appearance of liver.