

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MADELEINE FARRUGIA

I, Madeleine Farrugia, will say as follows:-

Section 1. Introduction

1. My name is Madeleine Farrugia. My date of birth is the GRO-C 1944. My address is GRO-C
GRO-C
2. My husband, David Farrugia, died of a brain haemorrhage. This was a result of being infected with the Hepatitis C Virus (HCV) from a contaminated Factor VIII (FVIII) blood product.
3. This witness statement has been prepared without the benefit of access to David's 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 Affected

4. My husband was suffered from mild Haemophilia A. He was treated at the Royal London Hospital (RLH), under Dr Brian Colvin. He was also a patient at the Addenbrookes Hospital, Cambridge (AH). We moved to Cambridge when David took an early retirement due to the HCV which was affecting his health.

5. When we married in 1965 obviously I knew that David was a haemophiliac, but it did not seem to affect his life too much as he was always in full time work and had previously served in the Merchant Navy.
6. Our daughter was born in 1967 GRO-C
GRO-C my grandson was born in 1993 GRO-C
GRO-C
7. During the 70's when the FVIII was the newest treatment available, my husband received it at the RLH from time to time but there was never any mention of a risk involved in this treatment.
8. When David's brother, Barry Farrugia was diagnosed and eventually died from HIV and various Hepatitis viruses, David spoke to Dr Colvin, but he was never told if he was infected.
9. Following this, in 2002, David's other brother Victor had also passed away. Having been diagnosed with HIV and HCV himself. David had now lost 2 brothers.
10. David was employed by London Transport for over 30 years and during that time, he hardly took any sick leave because of his haemophilia.
11. David was told he had been infected with HCV and possibly vCJD by Dr Colvin in the early 90's. all he was given was a leaflet to explain what it meant to be infected with HIV, how it may impact our relationship and what precautions we were to take.
12. When David had to have any procedure at the hospital or dentist, he would often be left until last because of his infection – this had a profound impact on his mental health and knocked his self confidence.
13. We moved to Cambridge when David was 62 to enjoy our retirement, but this was marred by his continual ill health due to his HCV.

Section 3. Other Infections

14. I am unaware of any other infections as a result of my husband's HCV.

15. We did receive a letter saying that David might be infected with vCJD.

Section 4. Consent.

16. I am not aware of any tests that would have been carried out without his consent.

Section 5. Impact

17. The physical and mental anguish of David's illness were numerous. Not being able to attend family functions, enjoy activities with his grandson or even going on holiday because he was so unwell at points.

18. He was severely depressed and spent a lot of his time in bed. This depression then of course had a huge impact on my mental health and my day to day living.

19. Our social life was non-existent and our retirement was not how we had planned it. After his death it came to light that David had confided in family members that he knew he did not have long to live by the way he was feeling. This still impacts on my mental health to this day.

20. Since his death I have been unable to come to terms with his death or the circumstances of his death. There have been no answers to the reasons why my husband and his 2 brothers were infected.

Section 6. Treatment/Care/Support

21. David or I never received any counselling. I wish that he did receive some counselling, I believe that this would have helped him greatly.

Section 7. Financial Assistance

22. David received £20,000 from the Skipton Fund and a further £10,000 a few years ago.

Section 8. Other Issues

23. There are no other issues.

Anonymity, disclosure and redaction

24. I do not wish to remain anonymous and I understand that this statement will be published and referenced by the Inquiry. I do not wish to give oral evidence.

Statement of Truth

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

Signed.

GRO-C

Dated

18/11/2019

MEDICAL SUMMARY

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

ADDENBROOKES HOSPITAL

- 03.05.78 Discuss with him (DF) and G S Davies (?) to go onto concentrate
- 13.09.78 Policy – change over to concentrate as his requirement is so low. Get Sister D to organize and remove cryo
- 26.08.83 Admitted swelling to knee. Treated bed rest then Factor VIII. LFT's were mildly abnormal
- 22.04.81 For the last fortnight has had increasing pain in the ?, ankles and hands. Can't sleep. Gets muscle spasms and pain in neck and shoulders. Feels exhausted
- 13.07.83 Has had occasional home bleeds which he has been reluctant to treat because of AIDS scare. Says he can't focus properly. Has lost 1.5 stone but not feeling ill
- 09.01.85 Despite what I have said to him he will not have treatment (Factor VIII) unless he absolutely has to. I have offered vaccine hep B to Mr Farrugia who will think about it
- 13.11.86 Clinical notes state "I have explained why I believe him not to be infected with HIV. I am sure he now understand this. We also had a long discussion about his brother's death and the AIDS problem and I think the air has been cleared to some extent.
- 28.01.87 Mr F now feels he would like to have hep B vaccine
- 29.07.87 Has had 2 hep B vaccines, 3rd one due in 1 month
- 17.12.87 Letter Dr Colvin to Mr Farrugiayour blood test is very satisfactory but you have not in fact made any antibodies to the hepatitis B virus as a result of your vaccination. This is not uncommon and it does not in any way mean there is anything wrong with you. I do not feel that a further vaccination is worthwhile at this stage.
- 28.06.89 Anti HBsAg negative

- 30.01.90 Anti HBc negative, HBsAg (hepatitis @B surface antigen) negative Anti HIV1 + 2 negative
- 30.04.90 Bloods taken for FBC, virology and LFTs with patients consent
- 24.12.90 Letter from BT Colvin The London Hospital to Mr Farrugia. I forgot to discuss with you the result of the hepatitis C test that was taken while you were in the ward. I do have a record that we told you the result but I am not sure how much time we were able to devote to discussion. Certainly you should be reassured that your liver function tests are currently almost normal and that all is well with you, but if you would like a further discussion with me on the issue perhaps you could telephone Sister Sheila Hayden for an appointment or we can talk about it when I see you again in March.
- 24.12.90 Letter Dr Colvin to Dr Dey Mr Farrugia's hepatitis C test positive but his liver function tests remain almost normal. Mr Farrugia knows that there can be long term consequences of hepatitis C but that these are really quite remote and that we will keep him under review. I have also explained that the evidence suggests that hepatitis C is not often transmitted sexually.
- 20.05.92 Clinical notes refer to feeling rough and thinks his liver is playing him up. He will wait until September and see Dr Colvin then as planned
- 07.05.93 Clinical notes state HBV, HCV, HIV negative
- 12.9.94 HIV neg, HCV pos,
- 24.05.95 I have explained that we have no clear evidence of liver disease though HCV PCR is positive. LFTs are generally normal and abdo u/s is normalI do not think that any specific action is required at present. Explanatory leaflet given
- 29.05.96 Mr Farrugia has declined a blood test today
- 28.11.97 Letter from Dr Colvin to Mr Farrugia "In recent weeks there has been growing concern about the remote possibility that new variant CJD (the human form of BSE) might be passed on by blood transfusion or even by the transfusion of blood products. Some batches of NHS factor concentrate which were issued a year or two ago have recently been withdrawn because of this concern, although the concentrate has already been used up. There is, in fact, no evidence that new variant CJD can be passed on by factor concentrates and it is very unlikely that this will occur. Nevertheless I feel I must inform you that you were one of those who received one of

the withdrawn batches of concentrate so that we can offer you a discussion about what this means.

- 15.03.02 clinical notes indicate HCV positive – no treatment
- 18.12.03 Letter BT Colvin to Dr Dey. He is really due for a hepatitis C review although when we saw him in 2001 it was felt that treatment was not indicated. I am reluctant to organise further investigation if he is going to be moving in the month or two and all this can be done in Cambridge when the time is right.
- 23.09.04 Letter Graeme Alexander Addenbrookes to Dr Hugenholtz. I was a little alarmed because in his history he gives a clear description of periods of extreme fatigue which would be quite characteristic of progressive liver disease and in my view might therefore constitute an indication for treatment
- 29.03.04 Had some bleeds around lower back. On demand home treatment with Replenate. Moving to Mack
- 23.09.04 Blood sample taken - Microbiology report – Hepatitis C Virus RNA detected, Hepatitis B negative
- 29.03.04 Blood sample taken – Microbiology report – Hepatitis A Ab positive, Hepatitis B core Ab negative
- 10.02.05 HCV RNA pos, HBV neg
- 10.02.05 Radiology report; no abnormality was seen in the liver, spleen, pancreas. No features of fatty infiltration or portal hypertension. No focal liver lesion identified.
- 11.03.05 Letter Tracy Woodal to Dr Hugenholtz. Ultrasound in November 2004 showed no abnormalities in liver. He reports bouts of fatigue but nothing else. Has been offered anti-viral therapy in the past but has refused this due to the potential impact on his lifestyle. He is, however, more receptive I feel to undergo therapy now.
- 15.03.05 Anaesthetic record for knee left inguinal hernia repair. Relevant medical history notes patient has acquired Hep C and vCJD whilst the admission sheet states vCJD exposure only
- 12.09.05 Blood sample taken – Microbiology report – Hepatitis C virus RNA detected, H.pylori antibody detected

12.09.05 Letter Dr Baglin Addenbrookes to Dr Hugenholtz. He is awaiting an appointment to commence a three month trial of antiviral therapy for hepatitis C.

06.03.06 Blood sample taken – Microbiology report – Hepatitis C virus RNA detected

20.06.06 Approach by Addenbrookes for funding for Pegylated Interferon and Ribavirin. Note that treatment did not commence until March 2007

17.08.06 Urgent request for LFTs in letter from Dr Hoare to Dr Hugenholtz. Mr Farrugia has developed new symptoms; worsening tiredness, itchiness and lethargy. He remains on the waiting list for treatment with pegylated Interferon and Ribavirin.

11.09.06 Radiological report – liver appears normal in respect to size, shape and echo texture. No evidence of diffuse disease or focal lesions

28.09.06 Letter Dr Gelson to Mr Farrugia. Because of the complications of biopsies in patients with haemophilia we are advising treatment for all patients with haemophilia, with just a single liver biopsy two years from treatment to assess disease severity at that point.

22.05.07 Letter Addenbrookes to Dr Hugenholtz. Week 4 on pegylated Interferon and Ribavirin. He reports tiredness as his main side effect

19.06.07 Letter Addenbrookes to Dr Hugenholtz. Week 8 on pegylated Interferon and Ribavirin. He appears to be slightly improved generally on therapy. He reports feeling tired and his wife tells me he is crabby and his shortness of breath continues.

18.10.07 Letter Dr Verma to Dr Hugenholtz. Hepatitis C RNA negative at 12 weeks post treatment with pegylated Interferon and Ribavirin.

17.04.08 Letter Dr Perry to Mr Farrugia. Your liver function tests are normal but you are aware that you have hepatitis C

08.05.08 Lettter Dr Verma Addenbrookes to Mr Farrugia. Unfortunatley the hepatitis C RNA is still detectable. We will continue to review you as planned in clinic

15.10.09 US Liver Doppler – liver appears of smooth contour and is homogenous with no liver focal lesions noted

04.10.10 Patient agreement to infusion of recombinant clotting factor and viral surveillance

- 07.10.10 US Liver Doppler – the liver demonstrates a smooth contour and appears homogeneous. Today, however, there is a small hyperechoic focal lesion noted in the right lower lobe measuring 6 x 4 x 6mm. no other focal lesions noted
- 01.11.10 CT abdomen – background liver normal appearances there are a few tiny hyper vascular regions in the periphery of the liver but no lesions greater than 5mm in diameter and no evidence of washout in the portal venous phase imaging. No evidence of malignancy.
- 26.04.11 Bleed earlier today – Factor VIII (can't read)
- 26.04.11 Letter Graeme Alexander Addenbrookes Hospital to Dr Howell. David came to the clinic today. His ultrasound shows no evidence of cirrhosis and his platelet count would suggest also that he doesn't have cirrhosis. Nevertheless because we can't be certain he continues to have ongoing surveillance in the long term and his next appointment will be with us in six month's time. We spent a long time in clinic discussing the whys and wherefores of hepatitis C transmission in the haemophiliac population and he is quite keen to have his second set of Skipton Forms completed. Fortunately he doesn't meet the criteria for those because he doesn't have cirrhosis or liver cancer or liver failure.
- 29.11.11 US Doppler liver and portal system. High frequency transducer reveals multiple small 2mm echogenic nodules throughout the liver. The previously noted hyperechoic lesion in the right lobe remains unchanged measuring 5 x 6mm. background liver texture is heterogeneous. Mildly irregular liver surface outline.
- 05.03.12 Pre-op assessment shows cirrhosis
- 06.06.12 Perioperative care record notes an *alert* - at risk of vCJD had transfusion from vCJD patient
- 24.01.12 Letter Mr Jani Hinchingsbrooke Hospital to Dr Howell. He has haemophilia and reports that he received a blood transfusion previously from somebody who was diagnosed with new variant CJD.

Mr Farrugia's notes refer to Factor VIII concentrates received – Lister, Kryobulin, Advate