

Witness Name: Karisa Jones

Statement No.: WITN2019003

Exhibits: WITN2019004-WITN2019021

Dated: 12 July 2019

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF KARISA JONES

I, Karisa Jones, will say as follows.

1. My date of birth is GRO-c67. My address is known to the Inquiry.
2. I make this second statement having now had an opportunity to consider my medical records, which were received after my first statement was submitted to the Inquiry in February 2019. I have only received my own medical records, and not those relating to my late husband, John Geraint Jones, which I am currently requesting. This statement therefore only relates to my medical records. This statement should be read in conjunction with my first statement.

Genotype

3. In my first statement I describe how, when I tested positive for Hepatitis C (HCV) and my genotype was the same as Geraint's, the hospital said he had passed it on to me. At **WITN2019004** is a letter from the hospital dated 1 June 2012 confirming this: 'Unfortunately her recent blood tests show that she has indeed contracted hepatitis C and is of the same genotype as that of her

husband's virus. It is therefore very likely that she [contracted] the hepatitis C indirectly through the blood and blood products that were given to her husband back in 1990.'

Geraint's treatment

4. At paragraph 11 of my first statement I described how we had to fight for a referral to Cardiff for Geraint to see the specialist and I would like to provide more information about this here. When Geraint was first diagnosed in hospital we were told that there would be a referral to the specialist in Cardiff. We waited for the referral and it didn't come. I phoned two to three times a day to try to get the appointment with the specialist sorted out as quickly as possible but it still took about two or three weeks before we saw the specialist. At the appointment we were told chemotherapy might prolong his life and that is when we both understood Geraint was dying. Geraint was called back to Cardiff a week later for the chemotherapy to start. It seemed like a very long time to wait for both appointments when Geraint was so poorly.

My treatment and follow-up

5. As described in my first statement, Dr Ch'ng advised I delay starting treatment because Geraint was dying. **WITN2019004** notes: 'I have explained to her previously that her fibroscan did not show any significant fibrosis and as both her and her husband currently have many things to contend with I do not propose any treatment in the short term and I have therefore arranged for her to be reviewed in 6 months time.' Dr Ch'ng told me treatment would make me ill, explaining that the side effects of treatment may include flu-like symptoms and nausea, and that it could have an impact on my mental health. The care I received from Dr Ch'ng and the nurse specialist was excellent: they kept me updated on everything that was going on and never hid anything from me. He

knew Geraint was dying and that if I started treatment immediately we wouldn't get that last bit of quality time together.

6. Geraint died on 28 September 2012 and Dr Ch'ng referred me for treatment three weeks later. A letter dated 29 October 2012 from the specialist nurse notes as follows, 'I spoke with her at length today with regards to treatment, the implications and possible side effects but she was very adamant that she wanted to go ahead with treatment today as she had prepared herself mentally for this. I have commenced her on Interferon alpha 2a 180mcg subcutaneously and also Ribavirin 600mg bd.' (**WITN2019005**). I also received Boceprevir in addition to Interferon and Ribavirin. This is not noted in **WITN2019005**, but is it mentioned in **WITN2019006**.
7. My first statement describes how I found this treatment, and my medical records confirm I suffered side effects including skin irritation, nausea with some vomiting, fatigue, flu like symptoms and bowel problems.
8. On 8 November 2013, after treatment had ended, a fibroscan was performed which had a result of 5.1kPA showing mild fibrosis (**WITN2019006**).
9. On 29 November 2013 there is a letter from the specialist nurse confirming I had completed treatment seven months previously and had cleared the virus. The letter notes, 'She is still having right sided pain particularly under her ribs. She has not had an ultrasound scan for 18 months approximately so I have arranged this for her. I don't think that there is anything for us to worry about and I have reassured her about this.' (**WITN2019007**). Despite this reassurance I have continued to experience pain in my abdomen.
10. On 5 February 2014 there is another letter from the specialist nurse confirming I had cleared the virus and discharging me from her care as follows: 'As you know this lady had a negative viral load six months post her antiretroviral treatment. I did however organise an ultrasound scan of her abdomen which was performed on 29th January. This showed a normal liver texture and no focal lesions seen. There was no biliary dilatation seen. Kidneys, pancreas

and spleen appear normal. She was obviously delighted by this news today. I have therefore discharged her from this clinic, should she need any input from myself at any time I will be more than willing to help.' (WITN2019008). I have received no further follow-up or monitoring since this time except yearly blood tests which I have to phone up to arrange. I had a blood test three weeks ago and am still waiting for the results.

11. Despite having cleared the virus in 2013 I continue to suffer with dreadful skin rashes and itching, so much so that I can scratch my skin until it bleeds and I have scarring from this. Ever since I finished the treatment I have felt completely washed out, and need to sleep much more than I did in the past. I still have pain in my abdomen, which I believe is from my liver.

Symptoms before diagnosis

12. My medical records contain all of my antenatal care notes for my children. On 24 January 1994 there is a letter to my GP confirming I had been booked in the antenatal clinic on 2 December 1993 and the letter sets out investigation results which included things like my blood group, etc. In the list of investigation results 'Hepatitis Screen' appears, and next to this is written 'not done'. (WITN2019009). If such a test had been done I do not know whether I would have tested positive for HCV at that stage in 1993, however, if anyone had ever given me advice about the risks of infected blood and asked me about risk factors in my life I would have told them straight away that Geraint had recently received many, many transfusions in 1990. This may have led to either Geraint or myself being tested for HCV in 1993.
13. My first statement describes how I went to the doctors about four years before my diagnosis with high liver readings and this was put down to the tablets I was taking. I have now had the opportunity to consider my medical records which show the following.

14. I was referred by my GP to a Dr GRO-D who I saw on 2 August 2000 following abnormal liver function tests in early 2000. The clinical notes for this and subsequent appointments are at **WITN2019010**. These notes record:

'GP referral → abnormal LFTs

LFTs: 5/00 AST 57

GGT 172

°H/O jaundice

Alcohol: ~ 4u / week lager

°H/O heavy drinking

°blood transfusion / °IVDA / last travel outside UK → 4 yrs ago → Mallorca.

No contact [with] jaundice. Urine always very dark

[...]

RIF (right iliac fossa) pain – under investigation

[...]

O/E obese

°jaundice

°signs of liver disease

°[illegible]

[...]

AS

Tender RIF/central abdomen

°[illegible]

°organomegally

[...]

Plan, alcohol

Hepatitis screen

Rpt auto-antibodies

Ceruloplasmin'

The entry is signed 'R Homewood'.

15. I recall seeing a doctor around this time and being told not to drink. I told her that I drank very little and she said it could be a reason why my liver readings

were high. I do not recall being asked any questions about my husband, his crushing injury, subsequent amputation or any blood transfusions he received. As set out above, if anyone at any point had explained to me the risks associated with infected blood and transfusions I would have told them about Geraint's transfusions in 1990 immediately.

16. Following this appointment there is a letter in my medical records from Dr Homewood, locum SHO to Dr GRO-D which says as follows (**WITN2019011**):

'Thank you very much for referring this 32 year old lady with abnormal liver function test since January this year. Her last AST in May 2000 was 57 and Gamma GT 172. Mrs Jones has no history of jaundice. She denies any heavy alcohol intake and takes about 4 units a week of lager. There is no history of blood transfusion, IVDA or travel abroad. Her urine, she noted, is always very dark. Her main complaint is pain and tenderness in her right iliac fossa and right upper quadrant, which is present on movement, on walking and especially on palpation. The scan of her abdomen in February 2000 showed a normal liver, spleen and kidney and a simple cyst in the mid line. For the last 2 years she has also suffered with constant diarrhoea. [...] There is no obvious jaundice or signs of chronic liver disease. [...] Abdomen is tender predominantly on the right side and there is a 3-finger hepatomegaly. [...] In view of the ongoing diarrhoea we have referred her for sigmoidoscopy and biopsy and also for barium enema. We have request a repeat ultrasound of her abdomen and blood tests including Hepatitis screen, auto-antibodies, ceruloplasmin. Dr GRO-D has seen Mrs Jones and agrees with the above. We will review her in 6 months time, at which time all the investigation should have been carried out.'

17. Further clinical notes from 21 September 2000 (**WITN2019010**) recording the results of the various investigations are exhibited and include an entry noting, 'Rt sided ABD pain mostly all the time' and the final line of this entry records

'Hepatitis screen –ve', though it is difficult to read what this last word is and so it is unclear whether the result of the hepatitis screen is in fact 'negative'.

18. A new entry in the same set of clinical notes also dated 21 September 2000 records 'Hepatitis screen –ve' (again, this entry is difficult to read).
19. The same clinical notes continue to 18 April 2001 concluding, 'Plan: since there is no sciatica type of pain and [illegible] stretch sign and no evidence of [illegible] dysfunction no further imaging advised. Reassured and advised to reduce weight and [illegible] posture and lifting. Discharged.'
20. A further letter from Dr Nour, SHO to Dr GRO-D dated 30 October 2000, records, 'I reviewed Mrs Jones in Dr GRO-D clinic today. She still has diarrhoea 3-4 times a day. Her weight is steady. She had an OGD in October 2000, which was normal. Duodenal biopsy was normal. Anti-endomysial, anti-gliadin, anti-mitochondrial and anti smooth muscle antibodies were normal. FBC, ESR and CRP normal. Profile normal, except gamma GT 145. Stool culture negative. She was seen by Dr GRO-D and we have prescribed her Loperamide 2 mgs tds. We have discharged her from the clinic but would be happy to see her again if necessary.' **WITN2019012**. There is no mention of a hepatitis screen or any results for such a test in this letter.
21. There are a series of test results in my medical records requested by Dr GRO-D including for 'Hepatitis A IgM' and 'Hepatitis B Surface Antigen', and both results state 'NOT detected'. The results are reported as at 4 August 2000 (**WITN2019013**). I cannot find any record or test result in my medical notes specifically for a Hepatitis C test before I was formally diagnosed in April 2012, 12 years later. I do not know why the 'hepatitis screen' referred to in Dr GRO-D plan above only seems to have resulted in a hepatitis A and hepatitis B test when it seems, in view of the questions I was asked about blood transfusions, alcohol, jaundice, IV drug use and holidays abroad, that what was being contemplated was hepatitis C.

22. With these results is a test for serum IgA on 29 August 2000 which was shown to be raised at 3.1 g/L (range 0.8-2.8) (**WITN2019014**). The result for previous raised GGT of 117 on 3 June 2000 is at (**WITN2019015**).
23. In 2002 LFTs were tested and the results were normal, save for raised GGT of 37 on 15 May 2002 (**WITN2019016**) when I was admitted to hospital with abdominal pain. The discharge summary dated 15 June 2002 records that I was 'admitted with right sided lower abdominal discomfort', but 'on examination the tenderness was situated more in the right upper right quadrant and an ultrasound scan confirmed an inflamed gallbladder wall'. I was given intravenous antibiotics and discharged, with a laparoscopic cholecystectomy planned as follow-up (**WITN2019017**). Gamma GT was still raised at 62 on 6 November 2002 (**WITN2019018**) when I subsequently underwent a laparoscopic cholecystectomy (gall bladder removal) in November 2002. The histology report showed mild chronic cholecystitis (**WITN2019019**). This operation did not ease the abdominal pain I have continued to suffer with and my medical notes frequently refer to abdominal pain.
24. In 2004, there is another GGT test result, also raised, of 64 from 3 December 2004 (**WITN2019020**).
25. As set out in my first statement I was very tired all the time for many years and suffered with flu like symptoms now and again. My GP records contain multiple references to muscle pain, aching joints and bones, lethargy, flu like symptoms, arthritis and rashes. As set out above, I suffered with right sided abdominal pain for many, many years and I can now see from my medical records that my liver function tests were abnormal for quite some time. I also suffered with depression for many years and my GP records also contain references to this. I understand that depression has been linked to HCV.
26. When I was diagnosed with HCV in 2012 a referral letter to the consultant gastroenterologist from my GP dated 12 April 2012 notes, 'Man[y] thanks for seeing this lady whose husband has recently bee[n] diagnosed with primary hepatoma – he is positive for hepatitis C following a transfusion. She is also

+ve – I enclose recent hepatitis screen. She is currently asymptomatic but does have slightly elevated liver enzymes – this is long-standing and she does have central obesity' (WITN2019021). I am surprised to see that my raised liver enzymes were known about for so many years but not further investigated.

27. I had said in my first statement that I did not experience any difficulties or obstacles in accessing treatment. However, now having seen my medical records, I am concerned that I ought to have been tested for HCV in 2000, 12 years before I was diagnosed, if not in 1993 at my antenatal booking appointment, 19 years before I was diagnosed. If I had been diagnosed with HCV all those years earlier then I could have been treated at that time, preventing years of damage to my body, particularly my liver, from HCV. Much, much more upsetting is that had I been diagnosed earlier then Geraint would also have been tested, his HCV diagnosed sooner and treatment offered. This might have saved his life.

Counselling

28. As I have set out in my first statement, neither Geraint nor myself were ever offered any counselling or psychological support in consequence of being infected.
29. My GP records note my GP suggesting counselling in August 2017 when I was feeling very low and it was agreed I would ring the Caxton Fund to ask about funding. This was suggested because the GP thought it would be quicker for me to get counselling via the Caxton Fund than via a GP referral because the waiting list was so long. When I contacted the Caxton Fund I was told they would have to put it to the manager but it wasn't something they could do straightaway. I was desperate for help and this is why I then paid for three sessions of private counselling, as referred to in my first statement at paragraph 47. The counselling helped me very much because the counsellor

made me feel very secure and allowed me to pour everything out. She was a stranger and at first I thought I wouldn't be able to talk to her but she made me feel very relaxed and I was able to get everything out of my system and it was like a weight had lifted from my shoulders. I would have like to have more than just the three sessions if I could have afforded it.

Statement of Truth

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

Signed

GRO-C

Dated12 July 2019.....