

Witness Name: Steve Farnell

Statement No.: WITN5220001

Exhibits: None

Dated: 1.6.22.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF STEVE FARNELL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 November 2021.

I, Steve Farnell, will say as follows: -

Section 1. Introduction

1. My name is Steve Farnell. My date of birth is [GRO-C] 1958 and my address is known to the Inquiry. I live with my wife and stepdaughter and work for a company called [GRO-C] as a materials handling team leader.
2. I intend to speak about my infection with hepatitis C ("HCV"), in particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on myself and my family, and our lives together.
3. I can confirm that I am not legally represented and that the position in respect of anonymity has been explained to me and I am happy for my story to be in the public domain. I am also aware that if I am critical of any medical professional or institution then they may have a right of reply.

Section 2. How Infected

4. I am unsure how I became infected with HCV. There are multiple potential routes of transmission, including surgeries I had in 1960-62, 1974 and 1975, which I will outline later and my volunteer work at St John's ambulance where I attended an amputation in the late 1990s and ended up covered in blood. There were other occasions in this line of work where I dealt with blood but we did take precautions and I always ensured that I myself had no exposed cuts or scratches.
5. I must also admit that I had sporadic period of intravenous drug use (IVDU). This was only for a few months around 1979. However, for this, I always used clean, sterile needles that were provided for my testosterone injections - which I will explain later, and I was conscious not to share.
6. Between 1960 and 1962, I had six major abdominal operations due to having Hirschsprung's disease, an inflammation of the colon resulting in impaired colonic motility. The Hirschsprung's disease took a couple of years to treat, involving surgical resection of the colon.
7. I was treated at Birmingham Royal Children's Hospital by Victor Brooks. I have to commend his tenacity in doing the surgery again and again as it saved my life. I do not recall personally due to my age but I believe that some of the operations for this would have involved a blood transfusion as they involved major abdominal surgery. My parents never mentioned this however - they were just grateful that I was kept alive. It was not something that we sat and analysed. It must have been a very emotive time for them knowing their child's life hung in the balance.
8. In 1974 I lost a testicle, with the other one having to be removed in 1975 via emergency surgery due to a medical oversight. From then on, I lost all my 'manliness' and had to take testosterone for the rest of my life. I am unsure whether I had a blood transfusion for these surgeries, however, I was in the hospital for about a week after the emergency surgery in 1975. I presume the

surgeons knew I was blood type 'O'. However, they would not have known that I am a "bleeder" - which I had been informed about after the previous surgeries. I have not tried to get the records for this surgery as I cannot change what happened and do not want to dwell on it.

9. The first testicle was removed as a result of pure bad luck from some sort of 'impact' accident I had as a boy. The second one was removed via emergency surgery due to testicular torsion. The doctors should have spotted it earlier due to the swelling and pain I experienced for about a week prior, however, there was a massive oversight on their part relating to this, particularly since I only had one testicle left. The twist of the cord happened on the, let's say, Monday and the pain progressed for a period of about a week. I was in immense pain and on bed rest. My mother called the doctor however, nothing was picked up and I was told to just rest, and put on a higher dose of antibiotics. Over a period of a week, three GPs were involved, and my mother finally took me to an emergency appointment at the Bristol Royal Infirmary as I was in so much pain. Within an hour of arriving, I was in an operating theatre having emergency surgery to remove the twisted testicle. This led me to become sterile.
10. My two younger brothers have had three children each, and it is painful to know that that is what I could have had if the testicle torsion had been picked up on earlier.
11. My parents took legal action against the hospital for this. As the doctors knew that I only had one testicle due to the surgery the year before, they should have been overly cautious and kept an eye out. This was dragged out for a number of years and was finally settled in our favour out of court.
12. I have subsequently had minor surgery in [GRO-D] and [GRO-D] [GRO-D] to have Testosterone implants put in. The minor surgery in [GRO-D] was a bit of a "dodgy" one, and the doctor doing it did not seem altogether with it. Within a couple of days, the wound had come open and I had to return to have a couple of stitches put in to hold the implants in place. I

have not had any other surgeries or medical interventions that could have involved plasma or a blood transfusion.

13. I have not been medically treated outside of the United Kingdom. I have no piercings and have one tattoo that was professionally done.

14. Prior to my HCV diagnosis in 2011, fatigue was the only symptom I experienced from the virus. I had a tendency to sleep all the time whilst not working. I thought that I may be anaemic and consequently had a blood test done at Nithsdale Road Surgery in Western-Super-Mare. A week later, my GP, who I had known for eight or ten years, phoned me back and asked me back into the surgery for a chat. He then told me that they had found antibodies in my blood that are only usually present when an individual has HCV. I was surprised by this news as I did not really know what it was, I knew that hepatitis was a liver disease, and could be quite dangerous, but I did not understand the severity of HCV at that time. Yes, I was worried but not overly so.

15. My GP asked me whether I drank – I did moderately, and immediately told me to stop. I have never touched a drop since, and I am conscious to eat healthily. At this point I was not given any information on what the infection meant for me going forward or regarding any precautions to take.

16. My GP subsequently referred me to the Bristol Royal Infirmary hepatology clinic, and I managed to get seen there fairly quickly. The doctors there took blood again as my HCV infection had to be typed, and it was discovered that I was HCV genotype 3A. I was then given leaflets regarding the treatment that was coming. After waiting for about a month for the drugs to be approved, I was given training on how to inject myself and then started the treatment.

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Section 3. Other Infections

18. Apart from HCV, I do not believe that I received any other infections from infected blood or blood products. However, I do believe that the HCV and the treatment for it have left me with medical conditions I would not otherwise have had to endure.
19. No mention of vCJD has ever been made to me.

Section 4. Consent

20. I initially consented to the blood test when I was being tested due to presumed anaemia. However, I was not aware that I was going to be specifically tested for HCV. After the initial blood test, I was tested again for HCV, and then again at Bristol Royal Infirmary to break the HCV infection down into a specific genotype. These tests I consented to.
21. Following the blood tests, all the treatment that I received was consensual.
22. I am not aware that I have ever been tested for HIV, however, I assume that the doctors would have done that at some point. It has never been mentioned to me and I have not wanted to bring it up.

Section 5. Impact

23. Before diagnosis, I felt very fatigued and was noticing that I would get incredibly drunk very quickly, to the point that sometimes I could not remember even after only a few pints. I did think this was odd but did not anticipate this could be related to anything more serious.
24. I have not had a biopsy to understand the level of cirrhosis in my liver, however, I have had multiple scans including fibro-scans, DEXA scans and ultrasounds. I have lost count of how many I have had now. As the cirrhosis

develops, I have developed cephalitis, and now have difficulty with names and memory. I was not fantastic before, however, I am certainly lacking now.

25. I was treated with Ribavirin and Interferon. I had to take Ribavirin daily, and inject myself weekly with Interferon, initially for six months, however, this was then extended to 12 months. I had regular blood works done during this time and was HCV negative within a month. At my fifth monthly check-up, I was told that the doctors were going to extend my treatment, although for reasons that I cannot remember. A month after finishing 12 months of treatment, I had more blood works done and was told that everything was clear.

26. The treatment side effects were horrific and included weight loss, sleep problems for which I was initially prescribed Temazepam, sweats, skin problems, uncontrollable itching, stomach cramps and throwing up, especially the day after the Interferon injections. "Ribo rage" and anger issues, brain fog and hair loss were other afflictions I experienced. Three months into treatment I also developed a Pilonidal abscess, where the hair at the top of your bottom starts to grow inwards. I suffered from enormous pain and developed a lump so bad that I could not sit down. I went to my GP, who referred me to be seen at the local hospital. When I was seen at the hospital, I had surgery within the hour. However, the removal of the ingrown hair and lump left a hole that could not be sealed. This had to be packed with dried seaweed every day for about a month, with no anaesthetic or pain relief, until the wound healed. The pain and level of discomfort was debilitating.

27. The treatment also went for my joints and I have problems with my left hip, nose, fingers and thumbs as a result of it. Furthermore, I have developed Trigeminal Neuralgia, also known as the "suicide disease", and I get excruciating facial pain and migraines, that sometimes last for up to a week. I had not previously suffered with any of these conditions or symptoms.

28. The first round of treatment was the worst, and I was sent on an anger management course by the hospital to deal with one of the consequences of the depression that had set in. I went a couple of times, however, each time I

just sat there thinking "Am I supposed to not feel good about this?". I did not think that it was doing me any good, listening to other people's problems. I had something to blame and just accepted it. I was supposed to feel depressed, fed up and angry. I recall that there was also access to acupuncture which I took advantage of, but did not help. The hospital had warned of the possibility of depression being a factor and had prescribed medication for it from the outset. I took this but as soon as the course was completed weaned myself off of the pills to prevent addiction.

29. Six months after the treatment finished, I felt slightly off. I booked an appointment to see the nurse, and when she looked at me and started to talk, I knew that it had come back. The HCV virus unfortunately had disappeared out of my blood system and had hidden in the fluid that surrounds the brain. And now it was active again. When I cleared the virus initially, I was ecstatic. I thought I can get on with my life then to be told that it was back, well the disappointment was tangible. It was a right kick in the teeth.

30. Unfortunately, as I had already had the HCV treatment on the NHS and it did not work, I was told I was not eligible for further treatment with the same drugs. I did not question this at the time. I just thought that is how it is but I decided to live a little and make the most of the life I had left as in my mind, I could be dead at any time.

31. For the next 6 years or so I was simply treading water, waiting to see if anything turned up. There was nothing mentioned about any other impending treatments. The hospital did keep seeing me as I was still being treated for a cirrhotic liver and undergoing scans and tests.

32. In 2015, a trial came up for a treatment that combined Interferon with a new American drug which I can't recall the name of. This lasted for six months, and my wife did the weekly injections. After the six months, I was HCV negative and after another nine months monitoring, I was given the real all clear in 2016.

33. The side effects of this treatment included rashes, itching and scratching, blisters on the soles of my feet which have stayed, and developed into a form of psoriasis. Significant, but not as bad as was caused by the first round of medication.
34. Despite the treatment clearing the virus, I have unfortunately been left with cirrhosis of the liver, and now have check-ups every three months. For now, it is a waiting game until the cirrhosis progresses, which I am told it will and I can get a liver transplant. Although I have not actually been told it, I have apparently developed liver cancer and I will update on this later.
35. The liver disease has ruined my social life, and I now have to overdose on lactulose to empty the toxins from my bowels every night. If I miss a night, I feel very groggy and fluffy in the head, which means I am rarely able to go out. It is also difficult to travel and stay over at friend's houses as I have to commandeer the bathroom for this.
36. My social circle has definitely gotten smaller since the diagnosis and treatment. As I did not want to go out during treatment and spent so much time away from socialising, or was no longer able to do the things I used to with friends, such as go out on one of my three motorbikes or go out to motorbike club, my social life has gone. I was quite outgoing and loved company but I now focus on my family and concentrate on trying to do my best for them.
37. The treatment has made me feel a lot more worn-out than I should do at 63. I do not think that I should have to be taking four distinct paths just to get out of bed. My quality of life has definitely decreased. I would like to be able to make plans after half-past five and go out for a pint after work. Luckily now there are some great non-alcoholic alternatives, and I am able to go out with my mates and pretend that I've got a "real" drink. There definitely seems to be a stigma surrounding not drinking or participating - at times my life seems to be one big lie really, and I am just playing a part.

38. Whenever I cut myself, I used to panic and was worried about the spread of the virus. I remember once going to GRO-D Hospital after I had cut myself and saying to the nurse that I had HCV. I was then made to sit in a corner away from everyone else. When I was seen, the staff were fully gowned, and the new packet of instruments that were opened to treat me were very obviously thrown away in front of me instead of being resterilised. I was made to feel dirty, and like I was an inconvenience to the staff. Following this, I experienced another stigma-related incident when a young nurse, whilst wheeling me down to the operating theatre, was telling everyone to step out of the way as I had HCV. The operating theatre doctor subsequently apologised, telling me that some people were frightened about HCV. However, it made me think as to whether they were adequately trained with regard to HCV and the infection risks.

39. The treatment has also impacted my personal relationships. During the first treatment, I was with my previous wife, and I think the treatment hastened the relationship breakdown. I realised when my first treatment failed that I needed to move on and that my life was running out. I needed to make the most of the time I had left. I had been seeing my current wife, Ziggy, as a friend throughout this period, and when her husband passed away, we tried a different path together. Ziggy has stayed with me ever since, and although I think she is a bit worried about the treatment and infection and all the possible ramifications, she is very tough. She never complains but I know deep down she must have a fear for the future.

40. My stepdaughter from my third marriage is aware that I am ill, but she does not know the full extent. We are very close, but I have not told her yet that I may have cancer.

41. I have also not told my mother or father that I have cancer. They are 83 and 86 respectively, and I am not going to be telling them that their number one son has got the big C. My mother is quite stoic. However, they are growing frailer in front of my eyes. As my two brothers do not live close, I worry that I

will pass before my parents and that no one will be there to support them, do the shopping, and generally look after them if I am not around.

42. My infection does not seem to have affected my relationship with my two brothers. They are supportive and we have an unusual, old fashioned gallows sense of humour that seems to get us through.
43. As soon as I got diagnosed with HCV, I saw the Human Resourcing (HR) team at work. I told them that I would have to have the treatment and that it would make me very ill, and it was decided that it would be better if I stood away for a period whilst I was undergoing treatment. The HR team were nothing but supportive, and created an alternative position for me during the treatment period. As I worked in materials handling and distribution, and used knives day to day, it was made sure that a bottle of bleach was kept at close reach within the building in case I cut myself.
44. Eight months into treatment, I had a slight scare. I looked so ill and had lost so much weight that I was later told that HR was thinking of pensioning me off and putting me into early retirement. Luckily, this never happened, and after 18 months in the alternative position, I was well enough to return to my main role.
45. During treatment, I was suspended from my fork lift and palette-stacker licence and had to retake both of those once I recovered. Luckily, I do not think that the diagnosis and treatment had an impact on my work and progression. I did not have sky-high aspirations, and the role, and requirements, of a manager, are no longer what they used to be.
46. The HCV infection has greatly affected me financially and I cannot get a mortgage or life insurance because of it. Through my company, I am insured for four years of salary via a death in service pay-out, obviously, as long as I keep working.

47. When I thought that I was not going to survive - because I did, I thought that the disease was fatal, I cashed in my pension and decided to spend it on more material things than I would have done, such as motorbikes, an expensive high-fi system, and lots of vinyl. I thought; 'what's the point', I may as well take advantage and live life to the full.
48. Once the second treatment worked, I curtailed my spending and realised how daft my previous spending choices were. I would not have cashed in my pension if I realised that the HCV was not something terminal. Unfortunately, I do not think my remaining pension will be enough to live independently in a privately rented house which all means I need to keep on working.
49. With cancer now on the horizon, I have gone back to the spending thought process I had the first time around. My best friend, Steve, passed away from liver cancer caused by liver haemochromatosis just before my diagnosis, so I have had a run through and know what liver cancer is like. My best school friend also passed away from sclerosis just from drinking, so I have also seen how that is.
50. I hope that the treatment I will now have to have for cancer will not affect my job or financial situation. Once I know for definite about the date for a liver transplant, I will have a word with HR.

Section 6. Treatment/Care/Support

51. No psychological counselling or support has been offered to me either at the time of diagnosis or during the two bouts of treatment. I spoke about my mental wellbeing with a nurse, Vicki, however, I thought that I could cope with the side effects of the treatment by myself - I had already been through so much and did not feel I needed it.
52. My dentist has always operated best practice so I have had no issues there.

53. Apart from the two incidences mentioned above, I have had no problems with treatment, care or support with regards to the HCV infection.

54. As mentioned above, I am close to being diagnosed with liver cancer. At a recent appointment with my consultant and following an MRI scan, my Li-rad reading was moved from 2 to 3. (This is a US scale used to depict the level of seriousness in respect of liver cancer). 3 is probable and when you reach 4 it is definite and a transplant is a necessity. As such my details have been transferred to the Royal Free Hospital pending a possible transplant.

55. UPDATE; As of the 8th of March 2022, I have now been diagnosed with liver cancer. Unfortunately, the tumour is in the centre of the liver rendering an operation and indeed chemotherapy out of the question. I have been informed that there is a new treatment that I will be started on in the near future.

56. I had an expectation that this would come around but it doesn't lessen the shock at the news any or diminish the worry that I have for myself and my family for the future.

Section 7. Financial Support

57. When I was diagnosed with HCV, I answered all the questions regarding routes of infection as honestly as I could. Very early on, I mentioned that I had experimented with IVDU as a teenager. I also provided details of the operations I had undergone as a child.

58. The fact that I mentioned this, despite the IVDU use being very infrequent and always safe - as mentioned I had my own needle supply from the testosterone injections, put everything out of the window with regards to being able to claim any form of financial support. The other possible routes of infection seemed to be dismissed out of hand and as such no mention was made to me of outlets that were available to claim support and assistance – not by any medical person.

Section 8. Other Issues

59. The infected blood scandal has not affected my confidence in the health service and I would not be here without them. Even with the failure regarding my testicles and how it has impacted on my life, I still have every confidence and as you can see, have availed myself of the service more than once since.

60. I was asked about a complaint that I made to the Bristol NHS Foundation Trust. I have no recollection of this and can only think that it may have related to concerns over receiving treatment for the HCV following the diagnosis in 2011.

61. From my experiences however, I believe that more education is needed for health care staff and the wider public, with regards to HCV and infection risks. If best practice is adopted within the NHS, then there should be no issue with dealing with someone who is HCV positive.

62. Update 01/06/2022: It was mid April 2022 when I was told I now had developed Liver Cancer. Things have progressed quickly. I had an Ablation procedure carried out in May 2022 and a follow up scan carried out on 25-05-2022. A telephone consultation is booked for the 9th June 2022 when the prognosis will be made clear.

Statement of Truth

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

Signed

GRO-C

Dated 01-06-2022