

Witness Name: Paula Jayne Hopkins

Statement No: WITN4382001

Exhibits: Nil

Dated: 8/10/2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAULA JAYNE HOPKINS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 June 2020.

I, Paula Jayne Hopkins, will say as follows: -

Section 1. Introduction

1. My name is Paula Jayne Hopkins. I like to be known as Jay. My date of birth is 1966. My address is . I am a former sea captain but I no longer work due to my ill health. 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 I received and the impact it had on my life.
2. I previously had a career at sea, working as a Sea Captain and Skipper. My last job involved working with disadvantaged children, but I am now unable to work due to my ill health as a result of my HCV infection.

3. I confirm that I am not currently legally represented and that I am happy for the Inquiry team to assist with my statement.

Section 2. How Infected

4. In December 1983, around 5 days before Christmas, my car broke down on Wetherby Road, Leeds. I got out of the car and started pushing the back of the car in order to move it out of the road. An eighty-two-year-old man with vision problems had not seen me doing this and hit me with his car. He said at the time that he thought he had hit a small animal or a bird and had no idea he had hit a person. Due to the impact of the crash I was thrown onto the windscreen of his car and then flew off, and was thrown through the air, landing on my knees close by to a petrol station which was some distance away from where I was hit. I was unconscious and bleeding so heavily that police who attended the scene thought I was dead.
5. I was taken to St James's Hospital in Leeds with snapped inner and outer cruciate ligaments, damage to my knee bones, a head injury and severe cuts to my face. I was kept unconscious for about a week in hospital and had emergency surgery for severe knee and head injuries. During this surgery I was given a blood transfusion. When I woke up in hospital I was told about how serious the accident had been and that I had been given blood. My father also remembers being told I had been given a blood transfusion during the operation as they had been worried about the blood loss and possible internal bleeding.
6. During the operations, I needed plastic surgery to address the injuries and scarring to my face. The skin on my forehead had been ripped back by the accident, exposing my skull which required plastic surgery. They grafted some skin removed from my buttocks onto my forehead. I was in a wheelchair for eight months before learning to walk again after extensive physiotherapy. I did receive financial compensation for this

accident and the driver admitted fault. However, the money did go quite quickly.

7. After the accident, I went through a bad patch and my life spiralled downwards. I had gone from being very active and even swimming competitively for Leeds to not even being able to walk for a long time. I was in a lot of pain due to my injuries and I also was suffering bad mood swings, attributable to the damage I suffered to my frontal lobe in the car accident.

8. I had come off the pain killers I had been prescribed following the accident, but was still suffering with the pain a while on. GRO-C

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9. In my mid-twenties, once my legs were working better and I was stronger, I wanted to start working and travelling again. When I was sixteen I had joined the merchant navy as I wanted to travel, however, it wasn't the kind of role I had had in mind and I left. I did enjoy the sailing aspect of the job so I decided to go back to sea but to work on yachts this time. This involved working away at sea a lot. Since I had sailing experience I was able to get this kind of work and I managed to work my way up the ladder. I was initially part of a crew and then became a first mate. When dropping off a yacht in Croatia, a company called Sun Sail told me to get my Skipper's ticket and come and work for them. I decided to take them up on this and ended up working as a Skipper for them. I also worked for Southern Sailing for a while, teaching and doing tours. I really enjoyed the work I was doing I loved being out at sea.

10. Around 12 years on from getting back to working at sea, a job came up which involved working with underprivileged children in care. This consisted of taking them out on a boat for twenty-eight days and getting them involved in working as part of a crew and teaching them how everything worked onboard. This usually meant working fifteen days on and then fifteen days off with a few months off over winter. It was a very rewarding role which I thoroughly enjoyed. It was great to see these children, often who had significant behavioural issues before the experience, adapt so well and be completely different personalities by the end of it.
11. Although I had no major health problems during this time I was still suffering with my knees and in my late thirties I saw a consultant in London about this issue. I was told the inner cruciate ligament of one knee was damaged and had not been repaired when I had first had surgery following the accident. This was because they did not have the technology to make this repair at the time. I was told I would need surgery to repair this. I paid for an MRI scan privately to avoid delays and with the consultant's support, I was able to have the surgery needed and recover over the three months sailing break I had over the winter. The surgery was done at Guy's Hospital in London as I was told the best surgeon was based here. I did not have a transfusion during this operation and I had no complications.
12. Having been fine health wise other than my knees, when I was around forty-four years old I started having some suspicious symptoms including back ache and problems with my bowels including loose stools. As I had a captain's medical certificate, I had some understanding about different medical conditions and I started thinking I may have an issue with my liver. At the time I just thought it might be some inflammation.
13. Around the time when I started to have these symptoms, my friend had read an article in the Daily Mail about HCV which called it something

like the 'silent disease'. The article said people in their 40s were starting to suffer symptoms of HCV only now, even though they had contracted it many years ago. As the symptoms described seemed to match what I was feeling, I decided at this point to get tested for HCV.

14. I was living in Brighton when I decided to get tested for HCV. I went to my GP in Brighton to get a blood test and was told that I was positive for HCV in a face to face consultation with the GP. I was completely shocked and had no idea it could be HCV. I thought it might be an issue with my liver but I thought it was just some inflammation.

15. The GP who told me that I was infected was very dismissive and had a really bad attitude. It almost felt like he was saying 'what did you expect' as he knew I was a sailor and there was definitely some stigma attached to this career as historically it was a male dominated profession and I felt he had made assumptions, incorrectly so. He did not provide me with any advice or support and did not even refer me to the hospital for treatment. I had to do my own research about HCV and took positive steps like cutting out alcohol without any advice from him. I cannot recall his name.

16. When I started to think about how I got infected, I was sure it was as a result of the blood transfusion I was given following the road traffic accident. Having lost so much blood to the point the police thought I was dead, I am sure I was given a significant amount of blood during the emergency operation I underwent.

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The tattoos I have had were all professionally done and I remember clearly how careful the lady who did them was when sterilising equipment and setting used equipment aside. I do not have any piercings. I have never been treated at foreign hospitals; on one occasion, when working in Tunisia, I suffered an injury but I refused an injection as I did not think it would be safe.

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Therefore, I believe the only explanation is that I was infected with HCV through a blood transfusion.

Section 3. Other Infections

18. I do not believe I was infected with any other infections during the blood transfusion. I was tested for HIV at the same time when I was tested for HCV and it was negative.

Section 4. Consent

19. I have always consented to all testing and treatment received apart from the blood transfusion, as this was during emergency surgery and I was unconscious. My father confirmed that I had lost a lot of blood and that he was not asked to consent to a blood transfusion but he said they had already operated on me and were worried about internal bleeding. He recalls that they were measuring my stomach every 15 minutes. He was a policeman at that time and they gave him full graphic details.

20. As far as I am aware I have never been part of any treatment or drug trial.

Section 5. Impact

21. After being diagnosed with HCV by my GP in Brighton, I had received no help or support and had not been referred to see a specialist. I had to take steps independently to find out more about the condition and did this by researching HCV myself.

22. As I had not received a referral from my GP and had no idea about the next steps I should take in relation to treatment, I decided to get in touch with the hospital in Brighton myself and managed to see a trained

specialist HCV nurse. He also gave me very little advice about my condition but told me that the treatment available for HCV only had a 40-60 chance of working. He said that since my viral load wasn't too bad and I generally looked fit and healthy, I should just wait and not have the treatment for now. I returned back to work after my winter break, I hadn't had any time off sick and I felt strong enough to resume working.

23. I did have a liver biopsy in Brighton in around 2009 or 2010 and it did show some liver scarring. However, my other symptoms had generally settled and I was not feeling too unwell at this time.

24. Although the specialist nurse in Brighton was not much help in providing me information about HCV, I do remember him saying that I did not need to tell anyone about the HCV diagnosis. This was because there wasn't really a risk of me passing it on to anyone so no one really had to know. I think he may have said this to me because of the stigma associated with HCV and how this could impact my life.

25. Sometime after this, I moved from Brighton up to GRO-C About a year after moving to GRO-C I noticed that my hair was starting to fall out and I was suffering from some other HCV related symptoms. I saw my GP who ran some blood tests which showed that my viral load had risen and was now very high. At this point I was referred to a specialist at Calderdale Royal Hospital in Halifax. He offered me HCV treatment which I started shortly after. The treatment offered was a combination of Interferon injections and Ribavirin tablets for 12 months. This involved weekly self-administered injections and daily tablets. I was shown how to administer these injections into my stomach by the doctor.

26. The specialist at Calderdale Royal Hospital did give me some background on HCV and the precautions that should be taken in order to avoid infecting someone. This is something that the specialist nurse in Brighton completely failed to do. I think I also had a Fibroscan here. I remember I needed this done as they were unable to locate the results of the biopsy done in Brighton.

27. The side effects of the Interferon and Ribavirin treatment were absolutely horrific and made me as weak as a kitten. I went from being extremely strong and fit to being completely floored. I had been told that some people do get very ill on the treatment and some don't but I was definitely in the 'very ill' category. I was also told that 80% of people lose weight and 20% gain weight but unfortunately, I was in the gain weight category and I lost all my muscle mass. I also suffered from further hair loss and brain fog. Luckily, I had someone who came in to help me as I was unable to do anything myself. This help was paid for by the money I received from the Disability Living Allowance and the Council. I believe the Council had a special funding policy to help people employ helpers if they needed support.
28. The first few months of treatment involved fortnightly visits and blood tests and then later on in the treatment, it became monthly. I told my work that I was extremely unwell and I was taking medication producing similar symptoms to chemotherapy. However, I did not tell them it was HCV. I received some months of sick pay during this time but eventually I had to tell them that I was not well enough to return to work which was very sad. I loved my job and having to give that up was very difficult. It was a very rewarding job and the best job I had ever done. I spent 8 years on that job.
29. At the end of the year-long treatment and after suffering the severe side effects of it, I was told it had not worked and there was nothing else they could offer me. They signed me off and I thought I had no options left. I felt like they were saying 'go away, die' basically, I was floored by it.
30. After being told the treatment hadn't worked, I was speaking to a midwife I knew, about this bad news and she told me that she had heard Bradford Teaching Hospital had really good HCV treatment. She said I should try and get referred there so I approached my GP about this.

31. My GP at GRO-C Medical Centre was really great and managed to get me an appointment with a specialist at the Bradford Teaching Hospital and he was great too. He told me not to give up and that there were new treatments finishing the last stages of trials which could help me clear the infection. He told me in the meantime to follow a specific diet, lose weight and get stronger so that I could cope with the new treatment when it became available. He also referred me to the Hep C Trust for support.
32. In about a year's time in 2012, the new treatment had become available and I started on it. This treatment still involved Interferon and Ribavirin but it also consisted of a new drug, the name of which I can't recall. This course of treatment was also going to take twelve months to complete.
33. Initially, after starting the treatment, my red blood cells took a nosedive and the doctor was considering stopping my treatment. However, they started me on injections that increase blood oxygen levels and this restored my red blood cells. I continued taking these injections for a few months while on the treatment in order to manage my red blood cell count. I had to go in every week for injections for 6 months. I had to queue to see the nurse for about an hour, receive my injection in my shoulder muscle, then have to go down to have blood taken, which again involved queuing down the corridor, it was always busy and it would take up to 2 hours.
34. I had to take the new medication with 20 grams of fat, twice a day and this caused me to put back on the weight I had lost. I had to set the alarm for 6:00 am in the morning, eat 20 grams of fat, take the tablets, then again at 6:00 pm in the evening. I was also suffering many of the same side effects I had with the first round of treatment, including the exhaustion. I started having problems with my balance which has continued to this day and I still have to take medication for it.

35. During the treatment I had to have weekly blood tests to monitor my condition. I needed to have help with getting to appointments and had to hire someone to do this for me.
36. Twelve months after starting the second round of treatment, I was given the all clear. However, the treatment and being so unwell during it had impacted my overall health. This included the mobility in my legs; I had gone from being so fit and active to barely moving for three years. I already had issues with my knees and this really exacerbated it.
37. As my knees were so unstable, I was referred to a specialist who performed an arthroscopy to clean it out, but eventually concluded I needed a new knee. He wasn't happy with this due to my age but as I was struggling so much, it had to be done. I had the surgery about four years ago now and recovering from it was incredibly painful. I had already been on painkillers for my knee issues before the surgery and had become desensitised to them. Although the recovery did take time I did get more mobility in my knee and leg. However, I do still have arthritis in this leg due to the broken bones I suffered. I have been told my other knee also needs replacing.
38. In around 2016/2017, I started getting chest pains. When I saw my GP at GRO-C Health Centre, she told me I probably had angina and referred me for an appointment at Calderdale Royal Hospital. While waiting for the appointment, I had another bad attack and saw my GP who was not happy that I was still waiting for an appointment. As she was worried about my condition, she managed to find me a hospital bed so I would be able to get treated straight away. I think she saved my life in a way and I have always been happy with my treatment with this GP.
39. After being admitted to hospital, I had surgery where I had two stents put in. I was told that the arteries were so blocked I could have had a heart attack if I hadn't had this procedure done when I had.

40. I still get chest pains from time to time and I use a spray when I get these pains. I am also unable to have the other knee replacement I need due to the issues with my heart.
41. I believe that the issues with my heart can be linked to the HCV treatment I received. Firstly, I was consuming a large amount of fat which was prescribed with the medication I was taking, although otherwise eating healthy meals. Secondly, I went from being extremely fit with a low resting heart rate to being almost immobile due to the side effects of the medication. Thirdly, I put on significant amounts of weight as a result of the treatment. I believe this combined with a family history of angina and being a smoker previously all contributed to my heart issues.
42. I also suffered from depression as a result of the HCV treatment and have been on anti-depressants for around 4 to 5 years.
43. Although I know that newer treatments became available shortly after I was treated and were much better in terms of length of treatment and side effects, my viral load was so high that I couldn't have waited for that treatment to become available. I have no regrets about taking the treatment I did, despite the terrible side effects.
44. One of the biggest impacts of the treatment was the effect it had on my working life. As I mentioned earlier, the treatment for HCV was so severe and intense I had to give up working during it. By the time I had finished the treatment, my knees had deteriorated and I had generally aged. You need to pass a strict medical examination in order to work at sea and there is no way I would have passed it after the HCV treatment. Due to the issues with my heart I have been told not to do anything too strenuous and will never be able to return to the job that I loved. This is very disappointing to me.
45. Not being able to work severely affected my financial situation. I had gone from earning a good amount to complete financial meltdown when

I could no longer work. I had some debts that I could no longer pay off as a result. I owned a property near Hastings which I sold to help cover my debts but I was unable to make a profit on this sale and it did not resolve my financial problems.

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46. I am lucky that my family and friends have always been very supportive of me throughout my diagnosis and treatment. My sister even said she would give me half her liver if she could. I told close friends about my diagnosis and they were supportive of me. I also informed my ex partners about my infection and told them to get tested and none of them were horrible about it; in fact, most of them just felt bad that I was so unwell. Luckily none of them tested positive for HCV.

Section 6. Treatment/Care/Support

47. I did struggle to get care for my HCV initially because, as I described above, my GP did not take the steps to refer me to a specialist when I was first diagnosed in Brighton. The hospital in Brighton was reluctant to offer me treatment as they seemed to think it wasn't very good and that it wasn't worth me having it as I generally seemed 'well'. However, I was later offered treatment at Calderdale Royal Hospital and at Bradford Teaching Hospital.
48. I did not struggle to get other medical treatment and I did not need dental treatment between the time I found out I was infected and by the time I had cleared the infection. However, at the time of my HCV diagnosis I had not been advised to inform dentists of my infection. I did tell the

surgeon who did my knee operation about the HCV and he had no issue with this, but I had already cleared the HCV by this point.

49. I was never offered counselling or psychological support when I was diagnosed with HCV or during the treatment. It was only when I went to the GP to talk about my depression to get antidepressants that they offered me some counselling. I had a few sessions but felt like the counsellor seemed to get more upset than I did, so I stopped going.

Section 7. Financial Assistance

50. After I had started treatment at Bradford Teaching Hospital, I was told about the Hep C Trust. I got in touch with the trust and explained my story to them and they advised me that I could make a claim to the Skipton Fund. I do not really remember what the questions that were on the form were but I remember completing an online form in around 2013. I don't actually think any of my doctors helped me with completing it.

51. In order to complete the form, I remember attempting to get my medical records from St James's Hospital in Leeds. When I called them, they told me that they only keep medical records for ten years before destroying them. Therefore, I decided there was no point in wasting money to request the records as they wouldn't exist. When I spoke to my GP about my records, the receptionist said that she had looked through my notes and could not see any mention of the transfusion. Therefore, I decided it wasn't worth paying the fee to request these records either. I am now aware that I am able to request my medical records without a fee through the IBI if I wish to do so.

52. Sometime after I submitted the application to Skipton, I got a rejection from them due to a lack of medical records and also because I had tattoos. [REDACTED]

[REDACTED]

53. The rejection from Skipton was upsetting as I knew my tattoos were safely and professionally done and I had tried unsuccessfully to get the medical evidence together. [REDACTED] GRO-C

[REDACTED] GRO-C

[REDACTED] GRO-C

[REDACTED] GRO-C

If I had been able to find some proof that I had received a blood transfusion I would have persevered with Skipton but I couldn't get this.

54. If I had received financial assistance from the Skipton Fund this could have helped me in overcoming some of my financial issues. I am still paying the Council back because they made an overpayment on my care plan and I hadn't realised. There was a private company who dealt with paying my carers and tax and national insurance so money would come into my account and go out to them, and I was that brain fogged and fatigued at the time from the treatment I was on, that I hadn't noticed the overpayment.

Section 8. Other Issues

55. I wasn't given infected blood intentionally as it wasn't known at the time so I feel that I have to get on with my life and be positive. However, I am giving this statement in the hope that it helps other people down the line. Falling ill changed my life completely and I can no longer do a job I love. It was also the catalyst to my other illnesses including depression. People infected should be offered counselling and given all the help and support they need. If my statement helps in any way I will be happy.

56. I have found the Inquiry team taking my statement to be very helpful and sensitive and they made a difficult process easier.

Statement of Truth

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

Signed

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Dated

8/10/2020