

Witness Name: David Johnson

Statement No: WITN5959001

Exhibits: WITN5959002-004

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DAVID JOHNSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 January 2022.

I, David Johnson, will say as follows: -

Section 1. Introduction

1. My name is David Johnson, my date of birth is GRO-C 1956. I live in GRO-C in Tyne and Wear and my full address is known to the Inquiry.
2. I was diagnosed with moderate haemophilia when I was 2 years old. I intend to speak about my infection with Hepatitis C ("HCV") which I contracted as a result of receiving blood and blood products for the treatment of my haemophilia. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me, my life and my family.

3. I currently live alone but I have been married twice and I have two children. My daughter, who is 41, is from my first marriage and she is the best daughter I could hope for. I got married in 1990 to my second wife, Elizabeth and I have a son, Jordan, who is in his twenties. I have a good friend called Theresa who I rely on. I was previously a self-employed painter and decorator. I no longer work and haven't done so for many years as I couldn't cope with my physical problems and was becoming unreliable.
4. I confirm that I am not currently legally represented and that I am happy for the Inquiry Team to assist with my statement.
5. The Inquiry's statement of approach has also been explained to me with the option to seek anonymity but I do not wish to.

Section 2. How Infected

6. When I was two years old, I cut my lip open and had to go to hospital because my parents couldn't stop the bleeding. It was in the aftermath of that bleeding episode that I was diagnosed with moderate haemophilia A. I was treated at the Royal Victoria Infirmary ("RVI") in Newcastle which is about 6 or 7 miles from my home.
7. Over the years, I have required lots of treatment intermittently for my haemophilia with cryoprecipitate and then later on with Factor VIII. As a result, I don't definitively know when I was infected with Hepatitis C. I found out that I had Hepatitis C in around 1992 during an appointment with Dr Peter Jones. I thought that the delivery of the diagnosis was rather blunt.
8. There have been about three occasions where I nearly lost my life through heavy bleeding episodes as a result of haemophilia, including a haemorrhage following an operation to remove polyps. After the

procedure to remove the polyps they sent me home at the weekend and on the Monday morning I was still bleeding from my backside which was embarrassing. I phoned the hospital to tell them that I was still haemorrhaging but I was told to wait as I had an appointment on the Friday to see the consultant. However, on the Wednesday or the Thursday I collapsed in the toilet and my friend Jan phoned for an ambulance and I was taken to RVI.

9. I mainly had bleeds into my muscles and joints, especially my legs and elbows. Most of my bleeds as an adult were caused through sport, and most of them from playing basketball.
10. As a child sometimes, I would be in hospital for months on end. When I was about 7 or 8 years old, I bit my tongue when I fell off my Dad's shed which took months to heal. I missed a lot of school as a result of my haemophilia and spent a lot of time in hospital. When I was little I used to cry for my mother and she used to stay with me as long as she could at the hospital and sometimes she used to fall asleep on the end of the bed. Sometimes the League of Friends would let her stay overnight and give her a bed in one of the rooms in the basement. One of the worst periods of my life was up until I was about 14 years old when I was constantly going to hospital to get treatment with cryoprecipitate. I remember they had to defrost it and it used to feel so cold when they administered the treatment that it made me shake throughout my body. They used to give piriton to counteract it.

Section 3. Other Infections

11. I do not believe I was infected with any other infections other than Hepatitis C as a result of my treatment with blood and blood products.
12. I have been tested for HIV but I cannot recall exactly when this was and fortunately, it was negative.

13.

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Section 4. Consent

14. I think clinicians may have taken my blood to test me for other infections without telling me, because other people have mentioned that contaminated blood had been known about since 1989, but I was not given my diagnosis until around 1992. I have heard of a lot of people saying that this happened. What annoys me is that the prisoners from America were getting paid to donate blood.

15. I got married in 1990 and had I have known about having Hepatitis I wouldn't have wanted to get married and have a family, and hurt anyone by passing it on.

16. I was a bit annoyed with Dr Peter Jones, when I heard on the news, that he said that he had pre-warned his patients that there was a possibility of getting hepatitis through the Factor VIII but he certainly didn't with me. I think if that was the case then we should have been given something to sign to say we had been advised of the risks as it is playing with someone's life really.

Section 5. Impact

17. I have always felt like I am living on borrowed time but that has allowed me to feel really grateful for everything that I have. Some days I have found it difficult to even get out of bed because of the physical pain, especially in my knees and that has given me a good perspective. I have good days and bad days. It is mainly at night time that is worse lying in bed with nothing to take your mind off it, you focus on the pain more. I get sharp pains through the haemophilia and have to concentrate on how

I am walking. I am falling over more frequently now because my knees and muscles are getting weaker.

18. I think having Hepatitis C has given me lots of long-term side-effects. A letter from Dr Yusri Taha (Consultant Physician – working in Dr Schmid's clinic) at the Freeman Hospital to Dr Simpson (my GP), dated 7 October 2021, lists all the conditions I have been diagnosed with, along with all of my current regular medications. (WITN5959002). The list is long. I have been diagnosed with liver cirrhosis, ulcerative colitis, type 2 diabetes, Crohn's disease, Bell's palsy and bilateral knee osteoarthritis. I am awaiting knee replacement surgery but I have put this off because I am frightened and uneasy about the operation and the recovery time. I have been told that I have a 40 to 60 % chance of losing a limb if I have the knee replacement surgery because of my diabetes.

19. At one stage, I was taking about 23 tablets in the morning and 30 in the evening for all different things including injections and medication for diabetes and Hepatitis.

20. A letter dated 21 March 2012 from Dr Kate Talks (Consultant Haematologist and Haemophilia Centre Director) at the RVI notes that I suffer from a series of significant chronic health problems. As a result of these chronic conditions I experience arthritic pain, fatigue and reduced energy levels. I also have hypertension and type 2 diabetes. The letter states that the control of this has worsened with my liver disease. (WITN5959003) I now require insulin for my diabetes.

21. I have to have regular eye screening tests every 3 months because my diabetes has got progressively worse to the point that it is now affecting my eyesight. I am waiting for an appointment from the Eye Infirmary at the RVI for laser treatment to treat a bleed behind my eye. I am desperate for my eyesight not to deteriorate further as it would stop me living my life fully. As I find it difficult to walk without crutches, I couldn't cope without

being able to drive. I really enjoy driving but I am not able to drive as much as I used to.

22. In around 2012 I was told by Dr Schmid that I have severe cirrhosis. My Fibro Scan results showed that my liver had deteriorated from 23 to 40 at that time. I had already developed cirrhosis by the time I received treatment for Hepatitis C. At that point I genuinely thought I would die within a few years. As a result, I made arrangements for my funeral and for what would happen to those around me after I died including sorting out my life insurance. I put £4,000 pounds away from the money I received from the Stage 2 Caxton fund payment to pay for my funeral. In November 2018, an MRI scan established that I had chronic liver disease. Although I still get the odd dull ache in one spot in my abdomen at night time, which I attribute to my liver, I think my liver has now stabilised in terms of its deterioration.

23. I have experienced periods of low mood over the years to the extent that I was prescribed Citalopram for depression and anxiety in the past but I haven't touched it for years because the tablets didn't agree with me and I would rather suffer with the low moods. Between December 2019 and February 2020, I was referred by the Haemophilia Centre to the Psychology Department at the RVI to get some help. I think I have gone back a bit in life and my confidence has taken a hit because of everything that has happened and that has been exacerbated by the stigma that I have suffered from Hepatitis C. A letter from David Hopper (Senior Physiotherapist) dated 1 March 2017, states that the stigma has 'severely impacted' on my 'psychological and emotional well-being'.
(WITN5959004)

24. With regards to the stigma associated with Hepatitis, around 4 or 5 years ago I went to a hairdresser to get my hair cut in Sunderland and I mentioned the hepatitis to the shop owner. She told me to come back as they were busy but there was only one person in there having their hair cut at the time. After that, whenever I went back, they always said they

were too busy even when it looked like they weren't and felt they were just fobbing me off. I can't recall why I told her about the hepatitis but it is something that I have never hidden. My fear is that they didn't want to cut my hair because of the stigma associated with Hepatitis C. My friend's neighbour suggested that I asked the hairdresser who lived above him to cut my hair, however, whenever I asked her she always made excuses. I used to cook curry for people's birthdays at the local karaoke night. My curries were really popular but the last few times I noticed that fewer people were eating them. I wonder if people have stopped asking me because they know I previously had hepatitis.

25. Holding a relationship down has been really difficult because as a result of Hepatitis C. For me, relationships have been such a good and important part of my life, but the stigma of Hepatitis C really gets to me emotionally. It is difficult for me to explain it to someone when I'm getting close to them. Intimacy was also particularly difficult due to the risks of transmission. Ever since I was a bairn I never thought I would be able to get married because of haemophilia, then the Hepatitis C added further complications and I class it as another hurdle in my life. I try to accept the problems in my life before they come. My life has been about making other peoples' lives easier and I always put other people before myself especially in relationships, then I get kicked in the teeth and you have to start again. I was in a previous relationship with a girl who I really cared about who was a Macmillan nurse. She used to help inject me sometimes. We got closer and then all of a sudden, she cooled off and I think this was because of the Hepatitis. I remember that when I first met Dorothy, her friend asked me early on if I had hepatitis or any sexually transmitted diseases and I thought this was odd at the time. I wondered if she had been enquiring about me on behalf of Dorothy as it seemed out of character although, I never confronted Dorothy about this. I had hoped that she would have had more understanding of my situation and I was really hurt when it ended. That is why my current relationship has been mainly friendship as I don't want to get hurt. I feel that I don't want to offer myself to a relationship now as I don't feel I have much to offer

because of my disabilities. I feel that all I can give now is me personally, and there is nothing else I can offer but I still feel good inside and I am not feeling sorry for myself I just want to make the best of what I have left.

26. I could never get a mortgage because of haemophilia and then the Hepatitis C as I had no financial certainty because of being in and out of hospital, although I didn't really need one as I lived in a council house. I was also refused life insurance because of the diabetes, although they weren't bothered about the Hepatitis.

27. I have itching and hair loss problems which is a side-effect from my liver problems and the Hepatitis C treatment as the Interferon is a cancer drug. I always get severe itches on my head, particularly in my ear and all over my body; particularly in my groin, legs, stomach, backside and chest. I have also lost a lot of my hair which I find unusual because no other family members have, and I used to have a thick head of hair prior to my HCV treatment. No one in my family has lost their hair.

28. My life has changed massively because of all my health complications. Hepatitis C has dampened everything for me. I used to love going out and listening to live music, but I do less of that now. I used to love playing sports but I had to stop it because it was too dangerous for me. I used to coach table tennis around schools in this area and attained the advanced coaching certificate. I also played volleyball and I also coached and refereed basketball and I had coaching certificates for both. I travelled all over the country with the Sunderland supporters club for basketball. It was a release valve for me, I would always leave feeling less stressed. I used to play a lot of sport which was a highlight for me then.

29. My mum who is now in her eighties, even to this day, feels guilty for giving me haemophilia because of all the complications it has led to. She feels responsible for all the problems I have encountered. I always tell her that's a silly thing to think because she's been a fantastic mother and I couldn't want for a better mother. Growing up I think my sister felt a bit

resentful as she thought the focus was all on me due to the amount of time my mum spent with me at the hospital.

30. I feel guilty all the time about the money I was given by the Caxton Fund as a result of contracting Hepatitis. I like to try to give back by helping people and I like to push myself to keep myself going otherwise you could just lie in bed feeling sorry for yourself. I try not to feel bitter about the hepatitis and I am grateful every day that I am here.

31. I have encountered so many difficulties in life that my approach is to just laugh at it and not take myself too seriously. I wouldn't change anything that has happened in my life. I like being the person I am and everything is an experience that you take something from. There is always somebody worse off in life. When I was younger, laying in hospital beds, I would feel sorry for myself, then I saw even younger kids with leukaemia smiling and I thought to myself, if they can be like that, then I can too. I think of myself as one of the lucky ones. I think this is only because I have pushed myself. I know that others have had it far worse.

Section 6. Treatment/Care/Support

32. In the main I can't fault the treatment that I have received at the RVI and take the view that if I hadn't received the Factor VIII then I wouldn't be here now.

33. However, as mentioned earlier Dr Peter Jones in his evidence to the Inquiry, said that he notified everyone about the risks of being treated with blood and blood products. I found that a bit strange and I was annoyed by it because my personal experience was that he didn't as he never said anything to me. I believe that I was infected in 1989 but I wasn't given my formal diagnosis until 1992. I believe that it was known about long before but kept hidden. If I am being honest, I sometimes felt a bit intimidated by Dr Peter Jones, he was a stern man and always very

straight faced. On the other hand, Maureen Fearn, the specialist haemophilia nurse, was incredibly kind. She was so good at administering treatment too, it never hurt or caused bruising and half the time I couldn't even feel the needle go in. I am now under the care of Dr Schmidt who is a lovely man.

34. I was informed that I had Hepatitis C at the RVI hospital. I think that it was a social worker who warned me about the risks of sexual transmission from Hepatitis C. They also gave me dietary advice about what was best for me which included avoiding alcohol. As a result, I changed my lifestyle altogether.

35. I have had three rounds of treatments for HCV. Unfortunately, the first two courses didn't work. One of those failed treatments was a combination of pegylated Interferon and Ribavirin. I also had a relapse after 21 weeks of triple therapy with Telaprevir. I think that they cut the second course of treatment short. I was told that the first course of treatment had about a 40 per cent chance of it succeeding for my genotype (1a). The course lasted for 9 months. The second course of treatment lasted somewhere between 6 to 9 months.

36. I had to inject myself with Interferon in the stomach once a week on a Tuesday morning and I would still feel terrible until the Thursday morning. I would feel sick and drained. For a day and a half after treating myself with Interferon, I would feel absolutely terrible because of the side-effects. I would try and just sleep it off. I wouldn't wish it on my worst enemy. That was a particularly difficult period of my life. It got to the point that my neighbour who was a pensioner would come and help me every day and made sure I ate, even if it was just biscuits and a cup of tea, because I couldn't take care of myself as a result of the drugs. Sometimes I couldn't be bothered to get off the settee to go to bed. The toilet was at the top of the stairs and I used the bannister rails to pull myself up the stairs.

37. In 2015, I had my third and successful round of treatment with Harvoni. It was a 12-week course and that worked really well. After just two weeks, my viral load dropped significantly. However, there were some side-effects including fatigue, muscles aches and pains, lots of nose bleeds and headaches.
38. Now that I am clear of Hepatitis C, I go to the RVI about once or twice a year for a check-up at their Haemophilia Clinic. I also get an ultrasound and Fibro Scan every six months at the Freeman Hospital. I also have an MRI scan once a year. As I have developed cirrhosis, these regular check-ups are part of my long-term follow-up and monitoring of my liver.
39. I have had endoscopies in the past. At one point, about 20 years ago, they found some polyps for which I had an operation to remove them. After that procedure, I suffered a significant bleed as I am someone who often has secondary bleeds. On that occasion I was not very pleased with the care I was given following the procedure. As a result of this experience I recently refused to have a colonoscopy because I knew it would cause me to bleed heavily. Dr Schmid mentioned that he wanted me to have a liver biopsy at one time, but the next time I saw him he said that they had decided not to as it might cause more damage and that they would get a more intense scan with the MRI.
40. I am really grateful to the medical staff that have treated me. I think they have looked after me really well and taken a genuine interest in me. Dr Schmid is a lovely man.
41. I have not suffered any stigma in relation to dental treatment as I always go to the dental hospital, rather than any local dentist, because of my haemophilia. Whenever I used to go to the dentist, I used to have to wait for about half an hour because after they got rid of one patient they had to wrap all the equipment and lights and things up in cling film. They wore full visors and gloves, the lot. This gave me a complex that I was contaminated and I used to think why all this for me.

42. I also remember one time on the ward when a nurse accidentally pricked herself after taking blood from me, I kept on asking if she was ok as it was on my conscience until she was tested and showed negative. I was worrying about her being infected.

Section 7. Financial Assistance

43. I remember getting a phone call from the Caxton Fund about potential financial assistance because of my severe cirrhosis. The hospital and a social worker helped me apply for financial assistance and I found the process straightforward. I received both a Stage 1 and Stage 2 payment in June 2011 when I received two separate payments from the Caxton Fund. I also receive monthly payments and a winter fuel allowance.

44. My social worker applied for an electric bed and an electric chair for me as I have a lot of difficulties with my knees. However, that application was rejected. The DWP took my disability allowance off me on two separate occasions and that included my Motability allowance.

45. I had to attend court to appeal the decisions and I had to go twice for medicals at Regent Centre, Gosforth. I had to go to court in front of a judge and a doctor because they still weren't satisfied. Both appeals were allowed and I won in both case and got the money refunded and back-dated.

46. I sometimes feel guilty about all the financial benefits that I receive and I feel grateful for the money I get each month. I am the type of person that likes to give in life, rather than taking from others and I always like providing for people.

Section 8. Other Issues

47. During the Covid pandemic I received a letter advising me to shield because of my health conditions.

48. A lot of people I knew with haemophilia who took home treatment died young after contracting hepatitis B. I didn't take home treatment because I didn't like injecting myself and I wouldn't let my mother do it as I didn't want to give her that responsibility. That decision saved my life.

Statement of Truth

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

Signed

GRO-C

Dated

17.2.2022

David Johnson

Exhibits

Exhibit No.	Description	Date
WITN5959002	Letter from Dr Yusri Taha (Consultant Physician) at the Freeman Hospital to Dr Simpson (GP) outlining diagnoses and current regular medications.	7 October 2021
WITN5959003	Letter from Dr Kate Talks (Consultant Haematologist and Haemophilia Centre Director) summarising medical history including infection with Hepatitis C and the significant chronic health problems.	21 March 2012
WITN5959004	Letter from David Hopper (Senior Physiotherapist) summarising mobility difficulties arising from chronic joint disease, and stigma of Hepatitis C and has severe impact on psychological and emotional well-being.	1 March 2017