Witness Name: Mrs Diane Rose
Roberts
Statement No.: WITN0222001
Exhibits: WITN0222002;
WITN0222003; WITN0222004;
WITN0222005
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MRS DIANE ROBERTS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9th November 2018.

I, Diane Roberts, will say as follows: -

Section 1. Introduction

1. My name is Diane Roberts. My date of birth is the GRO-C 1955 and my address is known to the Inquiry. I am a wife, mother of a blended family and a Glam-ma, as I insist my grandchildren call me!

2. I intend to speak about my infection with Hepatitis C following a blood transfusion I was given during surgery for an ectopic pregnancy. In particular I will cover, the nature of my illness, how the illness has affected me, the treatment received and the impact it had on me and my family.

Section 2. How Infected

3. In December 1979 when I was 24 years old, I was visiting a friend when I started to feel very ill with serious stomach pain. I caught the bus to go home at around 10pm and I found I couldn't stand up when I tried to get off the bus. I was bent double with pain and when I got home, I told my (now ex) husband I needed to call the doctor out. I wasn't someone who ever called the doctor but knew I needed medical attention. My GP (Dr Sides) came to the house and said he thought I had appendicitis and I should go to hospital. My brother drove me to the hospital where I was seen by a registrar. The registrar examined me, which included giving me an internal examination. I was diagnosed as having swollen fallopian tubes. I was sent home from the hospital around 2am, still in a significant amount of pain, and told to go and see my GP the following morning.

4. The next morning, I couldn't get out of bed. My mum and dad came to look after my 2-year-old daughter because my husband had to go to work. I felt so ill that I phoned the doctor from my bed to say I wouldn't be able to get to the surgery that day as the hospital had advised. I made an appointment for the next day because I thought I would be alright when the medication I had been given from the hospital kicked in. I slowly managed to get downstairs and I was lying on the settee when Dr Wilson, the female GP from the local surgery, appeared at the living room window. She asked that I take my time to get to the door in order to let her in. When Dr Wilson came in, she took my history then stepped into the hall to telephone a consultant who was a friend of hers in order to discuss my condition. When she came back into the living room, she told me she thought that I had an ectopic pregnancy. Dr Wilson called an ambulance and I was rushed to Hope Hospital (now called Salford Royal Hospital) in an ambulance. On the journey the paramedics struggled to insert an intravenous drip into my arm to keep a vein open. The GP said because of the urgency I was unable to wait for my parents returning with my daughter and so she kindly offered to await their return. Because I was very unhappy about being sent back to Salford Royal Hospital after the

misdiagnosis the night before and because the GP's consultant friend was mainly based at Hope Hospital, I was taken to Hope Hospital in Salford.

5. I later found out that the only reason the Dr Wilson visited me that day was because she had, by chance, overheard my telephone conversation with the surgery's receptionist. I was telling the receptionist that although the hospital had said the night before I was to go to see my GP the next day, I did not feel well enough so I would need to make an appointment for the day after. Dr Wilson thought that if the GP (Dr Sides) had advised me the day before to go to the hospital then my condition must have been serious as he was a very experienced doctor. Dr Wilson was very concerned and thought I shouldn't have been discharged. I have no doubt that if Dr Wilson hadn't spontaneously come to visit me that day, I would have died. I also later discovered that the internal examination I was given could have killed me because it was likely my fallopian tube had already ruptured when I was examined by the registrar and I also had a large ovarian cyst. I felt at the time, and still feel, that I was very badly mistreated by the registrar. When I discussed this with another GP at the surgery, I was told that the registrar had had his "knuckles well and truly rapped" but unfortunately there wasn't anything I could do because the registrar was protected by Crown Immunity.

6. I had to have immediate surgery for the ectopic pregnancy during which I also lost the ruptured fallopian tube and the surgeon removed the ovarian cyst. I understand I received 4 units of blood during the surgery and it was this transfusion which infected me with Hepatitis C. I had to remain in bed for the first 4 days and I was in the hospital for just over week to recover. I believe I was discharged quickly because they wanted me out of the hospital in the lead up to Christmas as this was around 13th December 1979.

7. Before my operation I was not told there was any risk of infection from a blood transfusion. I remember having to sign something before the operation but I don't really remember what I signed and nothing was explained. After the operation nobody discussed any risks with me or the

consequences of only having one fallopian tube remaining. When I went for a check-up with my GP, six weeks after my discharge from hospital, the only advice I was given was not to try for any more children for 6 months. Also, my GP couldn't be sure whether I would be able to have another child given the damage that had been done during the emergency operation.

8. I decided late in 1980 to try and have another child but I struggled to get pregnant so I went to my doctor and was given a drug claimed to promote the release of eggs. I was told to take it on the 5th day of my next period. However, I waited for my next period but it didn't arrive, so I went back to the hospital to discover that I was pregnant with my son and I later gave birth in GRO-C 1981.

9. In the early 90's when I was in my mid 30's I started to have flu-like symptoms. These would last for about a fortnight and would happen a couple of times a year. I would have no energy and it got so bad that at times I couldn't raise my head from my pillow and the whites of my eyes were yellow. I discussed it with my GP (different GP surgery than mentioned before as by this time I had moved area) who thought that my symptoms were hormonal and I was put on the mini-pill. This made it far worse as among other side-effects I put on 5 stone in under a year which I simply couldn't lose.

10. Around the time that I started having these flu-like episodes I read in the newspapers about a group of Irish women who had been given infected blood. I asked my GP about whether I could have been given infected blood via the blood transfusion I'd had, around 13 years before in 1979 and whether that would explain my symptoms. I was told that it wasn't possible that I was infected because there had only been one batch of infected blood. The reason I remember this so clearly is that I had a vivid picture in my mind of there being this one crate of infected blood somewhere in a warehouse. He told me that I hadn't received that

particular blood so I didn't need to worry and as a result of him explaining this I wasn't tested for anything.

11. I was finding it difficult to work, at this point I was working full time for Sefton Metropolitan Borough Council (MBC) in Registration and Inspection as well as looking after two children who were 12 and 16. I just didn't have the energy to continue doing it anymore but financially I didn't have a choice. It was at this point that my relationship with my ex-husband broke down and I moved to a house nearby together with the children. A few years later I was still struggling with my energy levels. I had started to work a second job because of the additional financial pressure of divorcing my husband and I was totally wiped out. Although the children were always very good, they were still very tiring.

12. Just before Christmas 1996 there was a blood donor drive in the area local to where I worked and I gave blood on the 11th of December 1996. It wasn't the first time I'd donated blood. I had donated both pre and post-transfusion. In the January of 1997 I received a letter from the National Blood Service in Liverpool which told me that my donation could not be used as I had Hepatitis C. The way it was worded made me feel like it said we're pleased to tell you that you don't have HIV but you do have Hepatitis C (**WITN0222002**). This was how I found out. The letter says that it encloses a factsheet about Hepatitis C and how to avoid transmission, I'm sure that it must have but I don't remember it at all and I did not save it although I did save the letter.

13. The first thing I did after I received the letter was telephone the National Blood Centre in Liverpool to ask how I could have caught Hepatitis C. I told them that the letter I received was unacceptable and I wanted to talk to someone about it. I made an appointment to see the Head of the Blood Donor Centre, Dr A J N Shepherd, and took my partner at the time along with me. The Head of the Blood Donor Centre was a consultant hematologist and he didn't seem very good with patients. He said that my blood had been screened as part of the donor process and the screening

showed that I had Hepatitis C which I already knew from the letter. I asked how it could have happened. The doctor asked if I had injected drugs or had a blood transfusion. After I said that I had not injected drugs but that I had a blood transfusion he looked at me and said that it didn't seem likely that I had injected drugs so I had probably contracted Hepatitis C from my transfusion. He told me that there was no cure but that there was research being conducted so there might be one in the future. At that point he told me that he thought I was "better off not knowing" that I had been infected. I wanted to punch him in the face and I'm not a violent person. He said nothing about taking precautions when it came to infecting others. I was given no literature.

14. During the same meeting I told him that I had given birth to a son after I had contracted Hepatitis C but he reassured me that it wasn't passed from mother to baby. I told him that even so, I would like to give my 15-year-old son the option of being tested as this had the potential of being a life changing event for him. I was told my son could be tested. Following this meeting I had to sit down with my son and explain that I had Hepatitis C. I told him I might have given it to him before birth or even afterwards as he continued to be breast fed after he developed teeth and thereby was capable of biting and drawing blood. This was enormously difficult and so very upsetting. GRO-C

GRO-C

15. My partner at the time GRO-C decided that he couldn't continue the relationship because of the risk of infection.

16. The only way that I could find out any more information about Hepatitis C was in the library and everything I read just said it led to cirrhosis of the liver and it was incurable. Although researching information at the time was difficult as this was pre-internet, I found out about an herbal treatment being offered in Brixton, South London. My GP managed to secure funding from Wigan Health Authority. The treatment was not intended as a cure

but something to improve my general health and liver and consisted of Chinese herbs and acupuncture.

Section 3. Other Infections

17. I do not believe that I have received any other infections.

Section 4. Consent

18. I believe that I was used as a guinea pig when I was offered the first generation of Interferon treatment in 2001. I believe this because the success rates at the time were so low and the treatment was so very new. However, because there was no alternative, I undertook the 48-week treatment. It was unsuccessful. A few years later I was greatly pressured to accept the second generation of Interferon treatment but I refused to undergo it as the success rates had not improved that much since the first generation. Because I refused the second-generation Interferon treatment, Manchester Royal Infirmary said they could do no more for me and wanted to discharge me. Therefore, I transferred to the Newcastle Freeman Hospital, as by this time I had moved house to Cumbria. Then along came the third generation Interferon treatment, Triple Therapy. I started the 48-week treatment in 2013 even though the success rate was still only around 30% for my particular strain of virus (Genotype 1). Once again this was unsuccessful. The reason I believe I was used as a test subject with regard to Interferon treatment is because once Harvoni treatment (with a success rate of 98-99% for my genotype) was developed and approved by NICE, I was told by Newcastle Freeman I wasn't eligible for it. The reason being, it was far too expensive for someone who did not have end stage liver cirrhosis! The way it appeared to me was, I was only able to receive the experimental treatments with low success rates to help with research. However, once a treatment was discovered with massive success rates for my genotype, the job was done. This meant, my services were no longer required and suddenly I was no longer eligible. Because I was refused treatment by Newcastle Freeman Hospital, I transferred to Dumfries and

Galloway Royal Infirmary (NHS Scotland) as we had since moved to Scotland a few years earlier. Here, I was offered the 12-week treatment with Harvoni and in 2016 I was told I had cleared the Hepatitis C. In 2017 I was told because I had a year-long sustained response I was clear of the Hepatitis C I had been given in 1979 and thereby was discharged from Dumfries and Galloway Royal Infirmary. I cannot speak too highly of my care at this hospital, of their dedication to their work and the respect they demonstrate towards their patients. I was told every step of the way of the procedures and potential outcome. This greatly helped me feel I was in control of my treatment. I had my own specialist nurse that I could telephone, text or email and expect a rapid response. A truly amazing hospital.

Section 5. Impact

19. Shortly after my diagnosis, after taking some time to think, I decided that I wanted to be sterilised. I came to this decision because I couldn't take the risk of giving birth to another child. There was no way I was going to risk bringing a baby into the world only to find out that I had infected them. It was traumatic enough thinking I may have inadvertently infected my son. I was 42 when I made this decision but before my diagnosis of Hepatitis C, I hadn't ruled out the possibility of trying for another child. Within weeks of making the request I was sterilised.

20. I think that I was so traumatised by the possibility that I could have, albeit unknowingly, infected my son. Having trained in childcare, I am very experienced with regard to babies and their care, knowing what is usual and what isn't. I have, for a long time, thought that my son may have had Hepatitis C at birth but cleared it in his first year. The reasons being, even though he was born three days later than expected GRO-C GRO-C and was a very sleepy baby. For instance, for the first month after birth he barely opened his eyes. There doesn't seem to be any way of knowing for sure whether he did contract it or not but I would not be at all surprised if he had.

21. In 1999 I met my now husband and I became more and more paranoid about giving him hepatitis. I decided I wanted to have a hysterectomy because it would reduce my chances of transmitting the infection sexually. I explained this to my GP who told me that I needed to have a medical rather than a psychological reason for wanting a hysterectomy. I had to fight the medical profession to have a hysterectomy because I was told that my fear of infecting my partner with Hepatitis C was not a sufficient reason.

22. Eventually, after much complaining, I was referred to St Mary's Hospital in Manchester to a consultant (Dr Donnai?) who fully understood the psychological impact of Hepatitis C on women. It was an unbelievable relief when he agreed to me having a hysterectomy. I seem to remember that he justified it by saying I had fibroids. After the hysterectomy I was told that it was a good job I had had one because they found pre-cancerous cells during the operation. Prior to the operation I had had a couple of abnormal smears but I was told that there was nothing to worry about as it quite often happens for no reason. I hadn't realised when I asked for a hysterectomy that I would be routinely tested for cancerous cells.

23. I had the operation on the Monday and on the Thursday of that week, at the age of 44, I started the menopause. The hospital wanted to put me on hormone therapy but as I wouldn't take anything by mouth my consultant found a topical gel that I applied daily until 2014 (when I had my first seizure) which kept my hormone levels stable and even.

24. In 2001, I was offered first generation Interferon treatment. This was a very difficult time for me workwise but I felt I couldn't refuse it as this was the first treatment, I had been offered with regard to Hepatitis C. The reason it was a very difficult time was because in the September of that year my job with Sefton Metropolitan Borough Council was being transferred to GRO-D and I would be working from home. The treatment lasted for 48 weeks and I was off sick for the whole of the time, from September 2001 to around August 2002. This year was exceptionally challenging, not only because

the treatment was so horrendous but because I was part of a new team of colleagues I had never met and who didn't know anything about me or my medical history.

25. The treatment was so awful, words cannot describe just how bad it really was. I have known people who have gone through chemotherapy and I'm not downplaying how bad that treatment is but, because people are familiar with chemotherapy and the effects of it, there is a greater level of understanding as to what one is going through. That level of understanding and support is so important when your body and even your life are under threat. Also, because there was such stigma surrounding Hepatitis C it was my 'secret', something I would only share with people I could trust confidentially and who I felt wouldn't judge. So, because I did not know my colleagues, I did not feel I could share the fact I was being treated for Hepatitis C. This left my husband and me very isolated and alone trying to cope as best we could both emotionally and financially as my husband had to give up work to care for me during treatment.

26. As a result, I retreated into myself and couldn't do anything. I remember sitting in a chair at home thinking that I could just fade away; that I could just go. Out of all of the challenges that I had faced since finding out I had Hepatitis C, of all of the metaphorical mountains I had climbed, this treatment just seemed too much. The treatment was almost worse than the illness. Throughout my life I've always felt there was hope but this called for far too much. It affected every aspect of my life. I didn't think I'd get past it. I did not think about giving up on the medication but I could have given up on life when sat in that chair as I just didn't have the energy to do anything about it.

27. Getting up in the morning was hard enough without even thinking about going out. My husband had to stop working because I couldn't cope on my own, I couldn't manage simple tasks such as washing my hair or getting dressed.

28. I was fortunate that a man in Australia kept a blog of his experience on Interferon treatment, the blog made me realise how the issues I was facing were due to the treatment. It also made me realise how bad the treatment was for others and that I wasn't alone. The man in Australia was suicidal.

29. After the Interferon treatment I started to suffer with severe psoriasis and this has continued. I believe the psoriasis was caused by the treatment. This has severely affected my confidence.

30. For the first 6 months I had off work sick, I received full pay and then it was reduced to half pay for 6 months. I didn't want to discuss my Hepatitis C diagnosis with my new manager so I decided to discuss it with the GRO-D central administration in London.

31. As I hadn't discussed my condition with my local managers, I would receive calls from them asking me to tell them about why I was off work so that they could help and support me. I found these calls quite aggressive at times especially as I did not feel comfortable sharing my highly confidential information. At some point the regional manager for the North West was informed by GRO-D Head Office in London that I had Hepatitis C. I then received a phone call from someone working in business support in London and I was told that I couldn't return to work until I had a "Free From Infection, an FFI Certificate". I told them if that was the case, given the nature of my condition it wasn't likely I would be returning to work so was I to consider myself sacked? The thought of going back to work with a new team who knew nothing about me, apart from fact that they now knew I had Hepatitis C, was horrible but by this time we were very much struggling for money so resigning was not an option.

32. I wrote to GRO-D to tell them that I was disgusted and appalled they had shared my information. I was so angry that in my letter I asked if when I returned to work, they wanted me to ring a bell and shout that I was unclean. I received a letter from HR apologising that the information had been shared. For me, their apology changed nothing, my personal information was out there without my permission and it couldn't be ever be

unsaid or the damage undone. I really had no other option but to start the job with this new team despite the fact that my Hepatitis C status had been shared. It was a difficult environment to work in. My husband wanted me to fight the breach of confidentiality at the time but I just didn't have the strength or the energy to take on my employer, GRO-D.

33. When the Equality Act 2010 came in I asked GRO-D for reasonable adjustments under the Act. I requested that I would travel first class so I would have a seat and ready access to food and drink. I also said I was unable to stay away from home as I suffered from anxiety when away from my husband overnight. In addition, I wanted 'Disability Days' to distinguish between being off sick and needing time off work due to disability-related disability because taking time off "sick" could result in disciplinary proceedings. I had a meeting with my managers to discuss the Reasonable Adjustments I believed to be necessary. I was accompanied by my Unison representative. The managers sat opposite my union representative and me and discussed between them, in detail, how much it would cost GRO-D to put the said adjustments in place! At this I became very upset and went to the toilets followed by my union representative. She said how unbelievable and outrageous the behaviour of the managers was. I remember saying "welcome to my world" as this was certainly not the first time, I had been treated in such a manner by this employer. My reasonable adjustments were eventually agreed but I certainly had to fight long and hard for them before they were. Looking back, I am still incredulous at how I was treated by GRO-D as an employee especially as my role was inspecting others and their policies and procedures.

34. Living with the stigma of having Hepatitis C has been so awful and will always be with me. It was like a mark of disgrace, something shameful. Until recently I kept it a closely guarded secret because people didn't (and still don't) understand what it is and are disgustingly judgemental about people who have it. As far as other people were concerned Hepatitis C was something that only people who injected drugs got. It was the dirty

disease. My opinion is that HIV became de-stigmatised far quicker than Hepatitis C has.

35. The stigma of Hepatitis C has totally rocked my confidence. I had always been a very self-assured positive person, very open and honest, always looking out for other people, making sure they were happy and safe. However, I found having to keep this secret meant it was hard for me to form new relationships with people who are not related. In terms of my career it meant I had very little chance of promotion as my health was not up to the challenge in the same way it had been some years before. This was especially challenging because I had always been a quite a high flyer who was offered opportunities, promotions and advancement sometimes without applying for them.

36. When I was a patient at a Penrith dentist surgery I was stigmatised when I attended by professionals who should have known better. My appointments were never with the resident dentist either, always the locum. It was made clear to me that I had to have the last appointment of the day because they said they had to scrub everything down more thoroughly after I'd been treated because I had Hepatitis C. I always wondered whether that meant they didn't scrub it down too well after everyone else. This was rather concerning especially as I'm sure not everyone would declare their health status regarding Hepatitis C. I have since moved to Murray Street Dental Surgery in Annan who I cannot speak more highly of. No stigma and certainly no shame.

37. I remember one time when I went to the hospital and on the outside of my file was a vivid yellow and black hazard warning sign. Not on the inside of the file but right there on the cover for all to see. When I was in hospital for my sterilisation, I was given a bathroom which was signed for my use only. At one of my appointments at Manchester Royal Infirmary the clinic was held in the Sexually Transmitted Diseases clinic and you had to sneak in around the back of the hospital. Looking back even I can't quite believe it happened, but unfortunately it did. I've even had blood taken when the nurse has put on an extra pair of gloves. When I tried to make a joke of it

saying, it would have been easier for them to wear a pair of Marigolds, they were quite huffy in reply implying it was my fault they were inconvenienced.

38. All these negative experiences and being treated unfairly meant I thought it was best for no one to know I had Hepatitis C. After all, if the medical profession, who were supposed to be educated in these matters, displayed such an atrocious level of ignorance, how could I possibly expect better from non-professionals?

39. Overtime, during treatment and following treatment, I had an underactive thyroid, and I am convinced this is connected to Hepatitis C and the corresponding treatment. I also believe that this is connected to my gaining weight and not being able to lose it as although I have now cleared Hepatitis C the effects of it on my body continue for many years to come. The weight gain, hair loss, rosacea, all have contributed to my lack of confidence and have had an adverse effect on my mental health and continue to do so.

40. I was offered second-generation Interferon treatment and I refused. I just couldn't consider the trauma of going through the treatment again especially as the success rates had not improved much. Also, by this time I had had substantial time off work with Hepatitis C related illness and wasn't financially able to lose any more absences through sickness.

41. Several years after the hysterectomy it became obvious, I had developed a prolapse and irritable bladder for which I was referred to Newcastle Freeman Hospital. The consultant said I couldn't have the operation I needed because of my other health problems. It was also made clear to me that when one has an infection such as Hepatitis C that is passed through blood they were only prepared to operate if the operation was lifesaving and not for any other reason. They said it would be subjecting the surgeons to unnecessary risk. Rather ironic I thought at the time. So, I had a pessary fitted, not something I was happy with by any means as I was barely in my fifties. I associated this with something people much

older than me would have fitted. In fact, when I moved to Scotland and consequently moved to Gretna Surgery, my new (wonderful) GP, Dr Idriz, said she thought I was far too young to have a pessary and why didn't I undertake a repair. Because I was still traumatised by my previous experiences and again because I wasn't financially able to have time off work, I refused. This gynaecological issue and subsequent irritable bladder once again contribute to my severe lack of confidence on a day to day basis making me feel a lot older than I am.

42. In 2010 I took early retirement and voluntary redundancy from GRO-D (I was an GRO-D) because, even though I was on a good salary, I knew that I didn't have any career prospects given my upsetting experiences since 2001 when I transferred. Between 2010 and 2011 I worked for GRO-D training childminders about registration and inspection under the Children Act 1989. I was made redundant in 2011, a year later. Following this I was offered a Team Leader post with GRO-D in August 2011. Before I accepted the job, I took the decision to tell them about having Hepatitis C. The Registered Manager offering me the job, thanked me for sharing and said of course the offer was still there and agreed I wouldn't have to do sleep-ins in the role as they would be detrimental to my health. I told her I would be grateful if she kept my diagnosis to herself and she agreed it was highly confidential and therefore she would not disclose it.

43. Within a couple of months of starting work at GRO-D, the Registered Manager, the person I had disclosed my Hepatitis C status to, left. Coinciding with the Registered Manager leaving, I became ill (Hepatitis C related). This meant I was off work for two weeks. On my return I telephoned saying I was coming back to work and thereby needed to know my shifts for the week. I was told I was doing a sleep-in that night and there were others planned later in the week. I told the member of staff that I had an agreement with the former Registered Manager that I would not be required to do any sleep-ins because of my health issues. The

member of staff said she didn't know anything about that but the Chair of GRO-D, said these were my shifts. I did the sleep-in that night and the next day I arranged to speak to this person the next day about the prior agreement with the Registered Manager not to work sleep-ins. At the meeting, after much badgering, I disclosed that I had Hepatitis C.

44. This person then shared my confidential health information with the Chair of GRO-D and other members of the management team (I was Team Leader of support staff). As a result, I was taken off all my Team Leader duties because I was infected with Hepatitis C., I was not allowed access to the service users or members of my team and was put on the job of cleaning the coffee machine and general cleaning duties. After weeks of being treated appallingly and being discriminated against, I walked out. I later telephoned and told them that it was impossible to work in the conditions I had been subjected to. I then received a letter from one the trustees saying I had breached my contract due to me not telling them I had Hepatitis C. I felt it was a repeat of everything I had been through with GRO-D and I didn't want to go through that ever again.

45. I researched what one had to do in order to take an employer to an Employment Tribunal and the day before the time limit for submission was up, I decided I would take GRO-D to a tribunal. It was an extremely difficult decision as it meant sharing the fact that I had Hepatitis C to many more people. However, I decided it was my information to share and the decision to share it was mine and mine alone and never would anyone take that from me in future. Also, I felt that nobody should be treated in such a manner whether it be staff or services users. When I started to have problems at GRO-D, I began keeping notes of my experiences, so I had evidence of everything that had happened and what I had been subjected to. From very early in the employment tribunal process I was made to feel like I was someone who was out to make a bit of money and not someone who had been discriminated against. At the preliminary hearing it was obvious to me an individual could not undertake an employment tribunal without legal representation. I contacted the

Hepatitis C Trust for advice as they had always been highly supportive in the past and was told no one had ever won a disability discrimination case for Hepatitis C. My household insurers were not interested, and I was not in a union. None of the legal professionals I spoke with would entertain the idea as they said I had no hope of winning the case.

46. When my uncle died in 2001, I had been executor of his will. Although this was now around 12 years later, I contacted Bob Haworth of Haworth Holt and Bell in Cheshire and explained my situation. Bob was wonderfully understanding and told me that although it wasn't his area of expertise one of the partners had just returned from paternity leave who he was sure would like the case. The other solicitor did in fact agree to take on the case, welcoming the opportunity. Because I knew taking GRO-D to an employment tribunal was absolutely the right decision, I went ahead even though I knew that I would have to write off legal costs. This was because as any award, would never cover my costs and there was the possibility that I would lose given the information I had previously been given. There was a four-day hearing and in the end, I won (**WITN0222003**). I wanted to shout it from the rooftops and share with the world but because GRO-D had three months to appeal the decision, I couldn't share it with anyone in that time. By the time I could tell everyone I was undergoing a second 48-week course of Interferon treatment and I was struggling with day to day living so not in a position to be vocal about the tribunal. Because I was not in a position to give the Employment Tribunal judgement the publicity I wanted and I felt GRO-D got away with discrimination as others were unaware of their behaviour. This left me feeling like they got away with it.

47. After I won my case, I found that I couldn't get a job because I had been to the Employment Tribunal. One day I walked into the local Newsagent and there was an advert for a temporary driver at the day centre. I walked across the road and spoke to the manager and she asked when I wanted to start. I loved that job even though it was minimum wage and part time as a top up to my pension.

48. In February 2013 I started my second round of treatment at Newcastle. This round of treatment had the same physical symptoms. In terms of the psychological harm, I knew the side effects that were coming but I'm not sure that made a difference to how I felt.

49. I felt that I had to tell my employers at the Day Centre about my treatment because I needed one day off a fortnight to travel to the hospital. This time I said that I was happy for the information to be shared but not while I was there. I wanted to have control over how people found out this time. That was a big decision because of my previous experience. The people I worked with didn't even know me, but were incredible. I managed to carry on working throughout the second round of treatment but when I came home around 15:00 I'd just sleep. I couldn't do anything else in the evening. I think that the second course of treatment was mentally better because other people were so accepting this time. They likened it to being on chemotherapy. It felt like a different world. The routine of having to get up but not having a lot of pressure was helpful as well. I didn't feel like I was going to vanish into the chair that time.

50. At the end of the treatment, 27th March 2014, I found that it hadn't worked again. I knew before they told me though. Things like your hair falling out tell you that it hasn't worked. Again I was told that there was nothing for me and they would see me in another year. I was told that there was research being undertaken into new drugs which would be available at the end of the year.

51. In July 2014 I set off to drive to my mum's house. The last thing that I remember is going to the garage before I got onto the M6 and then the next thing I knew there were paramedics and police. I later learned that I had a seizure while I was driving. I was in the hospital for a few days and during that time they did a load of tests because they didn't know what had caused the seizure. No reason was found why I would have the seizure. They wrote it off as one of those things but I knew it was the Hepatitis C treatment.

52. While I was in the hospital, I was told that although I might never have another seizure, I could no longer drive which meant that I lost my driving job at the day centre, I still find that difficult. The day centre offered to work out another job for me which wouldn't require me to drive but I couldn't think of anything that I could do. I lost my independence and my confidence following that seizure. So many small things that are difficult now. I got a temporary job a Marks and Spencer's over Christmas as I was no longer working at the Day Centre.

53. On New Year's Eve I had another seizure in front of my son and I think he was traumatised by it. I asked him afterwards what happened and he said that I was all over the place. The paramedic came from NHS Scotland. When he asked me which month it was said I replied and said September even though I was sat next to the Christmas tree.

54. The ambulance took me to Carlisle Hospital because they thought it would be quicker to be seen. I was told at the hospital that it wasn't worth having me admitted because it was New Year's Eve and I would be contacted in the New Year. Because I had now had two seizures they thought I might have epilepsy.

55. I was diagnosed with epilepsy shortly afterwards. When we had the appointment with the neurologist we sat down and he said oh I see you have contracted hepatitis C from drug use. He had never met me before but that was what was written there in the notes. I asked them to correct it but I don't know whether they did correct it or not as I do not have a copy of my medical notes.

56. I was transferred to Dumfries Hospital for my liver where I received the 12-week Harvoni and Ribavirin treatment. This is outlined in more detail in the section relating to treatment.

57. A few months after the Harvoni treatment I started having skin problems. In July 2017 I asked the specialist nurse what she thought of my skin problems and she said that it looked like a very even skin condition. I was

very worried it was lupus because I wouldn't have been surprised if I had had another autoimmune condition, because of my concern I went to my GP. The GP said it looked like rosacea but offered to test me for lupus. Following the tests, I was told that I had lupus. The GP offered to refer me but I didn't know whether I wanted her to refer me at that stage.

58. I went back in November 2017 and asked to be referred for the lupus. I was referred to a rheumatologist. I was referred to a locum from Glasgow who I didn't think was very pleasant in January 2018. He said that he didn't think it was lupus and said that he wanted to do more tests before he would decide to give me treatment. I just wanted to know what I had, I didn't know if I wanted anymore treatment. The Doctor took the view that I didn't have lupus after conducting further tests and finding that my inflammatory marker test was normal. I now have antibiotic cream which has greatly improved the condition for my skin and assume I will have to use it for life.

59. When you have to cope with the after effects of the treatment you realise that it's never going away; the consequences are never going away. At 24 I expected to be healthy and to live a long life. It has affected that and it's affected my appearance. I've lost teeth, I have rosacea, I can't wear contact lenses and I can't shift the extra weight. I can't see an end to it. I am 63, I should be retired. Not only am I not retired but I can't do the jobs I would love to do because I can't do any driving.

60. In terms of the impact on our finances I have outlined above the difficulties I have had in pursuing my career since my diagnosis. In addition, when I met my husband, he moved to Manchester to be with me because I earned more and because I was close to the hospital where I was receiving treatment. We were going to buy a pub in Cumbria which would be my husband's work to give us a second income. We were both trained to work at the pub and I would continue to work at GRO-D There were a number of issues with the pub and I was due to start the treatment so we decided that it just wasn't right for us.

61. After that we bought a home known as "The Old Lodge" in GRO-C so we wouldn't have to worry about a mortgage or rent if the treatment affected my ability to earn. However, my husband then couldn't work because he had to look after me. If he had got a job, he would have just been paying his salary for someone else to look after me. Not only did that not make financial sense but I didn't want other people around me. The house was a place of safety and I didn't want strangers to come in.

62. Over time we had to take a mortgage out on the house in order to live. We loved the lodge but it was hard to maintain and I was starting to struggle with the stairs. We decided to sell in around 2008 or 2009 but it took until 2011 to sell after we dropped the price. We took a £50,000 hit on the house because we needed to sell it.

63. Because we are not in a financial position to retire, I returned to work in December 2016. I got a fixed term job with GRO-D Council as a bundling clerk in Legal Services in November 2016. Once the term was up on this job I applied for other roles in the council and I am now a Business Support Administrator in Fostering and Adoption. I thoroughly enjoy the work especially as it in finance, but although the salary is reasonable, it is only half the salary I was on with GRO-D almost nine years ago and that was after a three year pay freeze.

64. I am presently in dispute with my employer, GRO-D Council and have lodged a grievance due to discrimination, harassment and breaching confidentiality. It feels like Groundhog Day with the actions of an individual manager making my life a misery. This is in an organisation who at very least should know better and recognise that with any chronic health condition there comes with the possibility of poor mental health and that not all disabilities are visible. It will be very interesting to see just how the assistant director hearing the grievance will react and respond. Just another example that my career is well and truly over.

Section 6. Treatment/Care/Support

65. I was not offered any counselling or support following my diagnosis or before my sterilisation. I was offered counselling when I later decided to have a hysterectomy but not at any point before that. When I did ask for counselling, I was provided with someone who was obviously used to dealing with people who had drug issues. My main source of support was a friend who I had been at school with who had chronic fatigue syndrome who could offer some understanding because of our similar symptoms. I later discovered the books of a liver doctor in Australia called Dr Sandra Cabot. Her book was called 'The Liver Cleansing Diet, Love Your Liver and Live Longer' and it gave me focus as it told me how I could try and get myself healthy.

66. I had my first liver biopsy in April 1997 at Salford Royal Hospital. I was told that I had to be awake so I wasn't under a general anaesthetic. The biopsy found that I had very mild hepatitis and no cirrhosis. Following my biopsy I wasn't offered any treatment and I was referred to Manchester Royal Infirmary because they had a specialist liver clinic.

67. Around this time, I remember reading a blog from someone in Australia who was undergoing a new treatment. The treatment only had a 13% success rate but it wasn't being offered in England.

68. I was still under the care of Manchester Royal Hospital when I got the results of a second liver biopsy in November 2000. In 2001 I was told that a treatment using Interferon and Ribavirin was now available and I agreed to start the treatment. I finished the treatment around about August 2002 and 3 months later I found out that the treatment hadn't worked.

69. I was offered the second-generation Interferon treatment and I refused. I just couldn't consider going through the treatment again until I could be guaranteed a higher chance of success. The second-generation treatment still only had around a 23% success rate. I was told that if I was refusing

treatment then there was nothing that they could do. I felt that they wanted me to have the treatment because I was being tested on.

70. When the third generation of "Pegylated Interferon" became available my husband and I read everything that we could about it. It had around a 30% chance of success. I asked for the treatment in 2006 but I was told that I would have to wait because I wasn't ill enough. The doctor was sat on the bed swinging her legs and told me she couldn't do anything to help me unless I lost weight.

71. I decided to transfer my liver treatment to Newcastle in June 2008. Newcastle Hospital had a Fibro scanner which showed in 2010 that my liver condition wasn't serious enough for treatment. In February 2011 I had another scan as part of my monitoring.

72. In February 2013 I started my second round of treatment with Pegylated Interferon at Newcastle Hospital. I also took part in a couple of studies. At this point I was identified as genotype 1. This was the first I heard about the different genotypes. There is a letter from the specialist nurse to my GP at the time I received the treatment warning that the treatment could cause psychiatric harm, especially depression. At the end of the treatment, 27th March 2014, I found that it hadn't worked again.

73. I went back in June 2014 and was told that there was a new drug, Harvoni, which NICE were currently looking into. The doctor said that they would know in October whether it would be available.

74. When Harvoni was introduced I asked for the treatment but I was told that I wasn't ill enough (**WITN0222004**). The results of the drug trials showed that it was 98% effective. When I was told that I wouldn't be eligible for the treatment I felt that I had been used as a guinea pig because the NHS was happy to give me the less successful treatments when I was part of a study, but now they had one that worked I couldn't have access to it.

75. NHS Scotland was offering the treatment and by this point we had lived in Scotland for 5 years so I decided that that would be my last appointment at Newcastle Freeman and NHS England. Therefore, I transferred to NHS Scotland and Dumfries and Galloway Royal Infirmary. I was briefly worried that I wouldn't be able to be treated because of the epilepsy but after consulting with a neurologist my gastroenterologist said it wasn't an issue. I was offered the 12-week treatment with Harvoni and in 2016 I was told I had cleared the Hepatitis C. In 2017 I was told because I had a year-long sustained response I was clear of the Hepatitis C I had been given in 1979 and thereby was discharged from Dumfries and Galloway Royal Infirmary. I cannot speak too highly of my care at this hospital, of their dedication to their work and the respect they demonstrate towards their patients. I was told every step of the way of the procedures and potential outcome. I was offered expenses for travelling to appointments and I was introduced to the pharmacist at my local chemist in case I had any further questions and I was able to drop in at any time to talk about my treatment. Also, I had my own specialist nurse at the hospital that I could telephone, text or email and expect a rapid response. A truly amazing hospital by far the best treatment I have experienced, and I have experienced quite a lot since 1979!

76. This round of treatment, which was the 12-week Harvoni and Ribavirin treatment was nowhere near as bad as the previous treatments. There were no daily injections only tablets 3 times a day. I felt very positive about the treatment. Maybe it was because I had fought to be offered this round of treatment, but it just felt right and also I had so much support from professionals and thereby was not as isolated as I had felt on the two other occasions.

Section 7. Financial Assistance

77. The Caxton Foundation wrote to me out of the blue in the early 2000's to ask if I wanted to register. I don't know how they received my details, maybe they received them from the GP or even the Blood Donor Centre in

Liverpool who had given me my diagnosis. Then, in November 2004, I received £20,000 in the form of a cheque from the Caxton Foundation as an ex gratia payment. In 2006 I asked whether I was eligible for Stage 2 payments, but I was told that I wasn't ill enough.

78. In 2013 I started to receive a discretionary winter fuel payment from the Skipton Fund which was around £500 at the time.

79. In October 2013 I applied for money to pay for a cleaner and a gardener because I had been unable to do these things myself while I was undergoing treatment. I received £1604.43 from the Skipton Fund for financial assistance while undergoing the 48-week long treatment.

80. In 2014 the Skipton Fund wrote about the winter fuel payments and said that because of new beneficiaries they had to drop the payment to £340. I think there were objections to this because in March 2015 I received another £150 towards winter fuel payments from the previous year.

81. I was told in July 2015 there were regular payments which could be applied for under Stage 1. However, because of mine and my husband's joint income, and the fact that we didn't have children at home, we weren't eligible.

82. In 2016 I asked the Skipton Fund for around £4000 to put railings around the patio and outside the entrance to the kitchen because they are raised about two feet from the ground and I was worried, now I had epilepsy, about suffering from a seizure and falling. Although I had obtained quotes for this work which confirmed it would cost £4000, we were offered only £1,500 in April 2016. This means as the patio and kitchen entrance are still unprotected, for my own safety, I can't go outside the back of my house when I am on my own.

83. I did receive a grant of £508.59 per month for three months which covered my loss of earnings whilst I was on the Harvoni. I was led to believe that I was heading toward cirrhosis before I got the Harvoni, so I was going to apply for stage 2 payments but then thankfully I was cured.

84. In October 2017 I had just had my lupus diagnosis when the England Infected Blood Support Scheme (EIBSS), who had recently taken over from the trusts managing support funds for people such as me who had been affected, announced that you didn't have to have cirrhosis to apply for Stage 2. You could have an autoimmune disease caused by the Hepatitis C or had a bad reaction to treatment. They announced that if you applied for Stage 2 payments before January 2018 then your payments would be backdated to October 2017. I wrote to EIBSS to say that I was waiting to see a Rheumatologist to confirm diagnosis and therefore I needed the time limit to be extended so I could still receive backdated payments. They agreed to extend the time limit until March 2018. They then agreed a further extension to 14th May 2018. At this point I had been discharged from specialist liver care, so my GP had to sign my application. I got my application in on the 14th of May 2018 and I had an acknowledgement to say it had been received.

85. EIBSS then wrote back to say that they couldn't see the link between my current health problems and my Hepatitis C diagnosis or treatment. I sent them additional information from several different hospitals (I have been a patient of about 8 in total) as well as a letter explaining the link myself (**WITN0222005**). I then received a letter to say there was a backlog so there could be additional delays in determining my case.

86. Eventually they agreed that I would receive stage 2 payments but they said in the letter that they would only backdate it to the 1st May 2018. EIBSS refused to accept that I had been offered an extension on backdating payments until October 2017.

87. I phoned EIBSS the next day and stated that I had the letters in which they agreed to the extension. They denied sending the letters as they didn't have any record of them. I asked them to check my file and I was told that they wouldn't be in my file. The woman on the telephone told me I had to write in and appeal. I said that it wasn't an appeal because it was their error but she said that this was the only option.

88. I wrote in to explain what had happened. I sent copies of the letters via registered post that EIBSS had sent to me agreeing the extension. Thirty-one days later (EIBBSS said it would take up to 30 days to reply) I telephoned to say I hadn't heard anything. I was told by someone at EIBSS that they hadn't received anything. I told the woman on the telephone where I had sent it to, and she denied EIBSS had received it even though it was a tracked delivery. She telephoned me back about an hour or so later saying they couldn't find my letter but as a gesture of good will they would pay the postage if I sent it again.

89. I telephoned GDPR commission and they informed me it was a definite breach of security and because it was a mishandling of "ultra-sensitive health information" she gave me a list of things that I should do. EIBSS telephoned back before the end of the day as I had told them they had to and told me that she had found it "in a box" because they were in the process of moving from London to Newcastle and it had just been packed away. I told them I would be reporting them for a data breach, and she replied that her manager would have to look at the case before giving an answer on my appeal and I told her there would be serious consequences if they didn't.

90. EIBSS telephoned me at the end of the week and said that they would backdate the payments to October 2017, but they never acknowledged they had sent the letters agreeing to the back-payment. When I was told that I would get the backdated payments the woman on the telephone told me that she didn't know I'd been given an extension!

91. I was told that they couldn't tell me how much money my backdated Stage 2 payments would be because it needed to be signed off. They also told me they didn't know when it would be signed off. They telephoned me the following Monday to tell me the amount to be agreed and that it would be in my bank on the 15th of November even though I had been waiting from the 20th of September 2018.

92. Initially I was receiving around £750 a quarter under my stage one payments and then from April I was receiving £333 a month. Now under Stage two I receive £1,500 a month plus the fuel payment of around £500 a year.

93. In February 2018 I received a letter from EIBSS regarding the frequency of my payments. At the time that I received the letter I was receiving payments quarterly. The letter stated that once I decided the frequency of my payments the decision could not be changed until the next financial year. At this point I started to receive monthly payments. I telephoned EIBSS early in February this year and made the request to revert from monthly payments to quarterly. I was told this was not possible I had made the decision last year to receive monthly payments and that decision was permanent. I told the person on the phone that this was untrue as I had a letter stating that it could be changed once per financial year. Again, my request to change my payment frequency was denied. I was told that there was no appeal process but that I could send in an email. It took a week for them to respond to my email and the only thing contained in the response was a request for my date of birth. I am still waiting. It seems to me that whatever I ask of EIBSS the answer is a firm "NO". If you then complain it is dragged out until finally, they concede. During this period of appeal and indecision I feel overwhelmingly powerless and frustrated.

Section 8. Other Issues

94. There are no other issues about which I wish to give evidence.

Statement of Truth

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

Signed GRO-C

Dated 11.05.2019