Witness Name: H L Campbell
Statement No: WITN3572001
Exhibits: WITN3572002 –15
Dated: January 2020

FIRST WRITTEN STATEMENT OF
HELEN LOUISE CAMPBELL

I, HELEN LOUISE CAMPBELL will say as follows:-

Section 1. Introduction

1. My name is Helen Louise Campbell. I am single and live at GRO-C, GRO-C. My date of birth is GRO-C GRO-C 1971. I retired on ill health grounds nine years ago from the NHS where I worked for many years as a co-ordinator for the Expert Patients Programme.

2. As a result of receiving contaminated blood products and contaminated blood I was infected with Hepatitis C. I was a spontaneous clearer but my Hepatologist confirmed that I have cirrhosis from being infected with the virus.

3. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How infected

4. When I was very young, I was initially treated at the Leeds General Infirmary (LGI) under the care of Professor Scott, Consultant Paediatrician. I was then

cared for by the Paediatric Department at St James' Hospital (SJH) in Leeds under Dr L Swinburne, Consultant Haematologist before being transferred to the adult Haemophilia Centre under the care of Dr McVerry, who was the Head of the Haemophilia Unit at SJH. In my early 30s, due to my dissatisfaction with Dr McVerry (see later), I decamped from this Haemophilia Centre and moved to the Haemophilia Centre at the Royal Hallamshire Hospital (RHH) in Sheffield. I received exemplary care from Professor M Makris, Reader and Honorary Consultant in Haematology at RHH.

5. When I was a baby and a toddler I suffered nose, gum and joint bleeds and endured terrible bruising. I had a particularly severe bleed in my left ankle joint which left me with lifelong difficulties and permanent damage. My (adoptive) mum once found me in my cot completely covered in blood. She was a Nurse Tutor and asked Professor Scott to investigate the bleeding symptomatology I had experienced since birth.

6. Professor Scott subsequently diagnosed me with severe Von Willebrand's Disease (VWD), when I was aged around 3. This was confirmed to be Type III, which is the most severe type, by Dr McVerry when I was aged 28. Due to the fact that I was adopted at 10 days old no family history was available.

7. Shortly after my VWD diagnosis, I was admitted as a paediatric inpatient to LGI, aged 3, for a severe nosebleed (epistaxis) which was packed so tightly that the blood started coming out of the tear ducts in my eyes.

8. In August 1984, when I was still aged 12, I suffered a particularly bad left elbow bleed (haemarthrosis), following two months of intermittent pain and stiffness. **Exhibit WITN3572002** is a copy of a letter dated 16th August 1984 from Dr L Swinburne, Consultant Haematologist, to Dr Cook, General Practitioner, which states "*This young girl came up with acute haemarthrosis in the left elbow. This followed two months of intermittent pain and stiffness. She was given three units of Cryoprecipitate which showed an immediate improvement. However, when I saw her on Thursday 16th August there was still an effusion with limitation of movement so I gave her a further dose*".

9. GRO-C

10. **Exhibit WITN3572004** is a copy of an extract from my medical records which states "*12/10/84 got slapped on the elbow last week 1000 u Factor VIII. To home prophylactic (!) doses next week X 2*". I have no idea why a medical professional has recorded an exclamation mark on my medical records.

11. GRO-C

12. From 1971 to 1989, I believe that I was treated with Cryoprecipitate, Factor VIII concentrates, Fresh Frozen Plasma (FFP) and whole blood transfusions.

13. **Exhibit WITN3572005** is a copy of my treatment record from the National Haemophilia Database (UKHCDO).

14. **Exhibit WITN3572006** provides the only evidence of the batch records that appear within my medical records which I believe do not encompass the full set of records. This document is entitled "*Factor VIII Record Card*".

15. I was never given any information or advice regarding the risks of infection from Cryoprecipitate, Factor VIII concentrates, FFP or whole blood transfusions. I am also certain that my parents were not informed in relation to any risk; my mum accompanied me to all of my appointments up to when I reached the age of about 19 or 20. Despite the fact that my mum worked full time she had flexibility in her working hours and her holidays often mirrored mine.

16. However, having gone through my medical records I have located two letters which I have not had sight of before. These talk about the risk of Hepatitis and are exhibited at **Exhibit WITN3572007**. The letters are dated 8th June 1983 and 6th July 1983 and are both addressed to me personally, which seems very odd given that I was aged 11 at the time. My view is that it is certainly possible that these letters were created at a later date.

17. **Exhibit WITN3572008** is a copy of my Hepatitis C virus antibody test result. The results arrived on 24th August 1990 when I was aged 18. Prior to being tested for Hepatitis C, I should have been informed what I was being tested for and the ramifications of a positive result so that I would have been somewhat prepared for the worst case scenario.

18. **GRO-D**

19. GRO-D

20. GRO-D

21. I also joined a Hepatitis C support group in Yorkshire which consisted of four people including myself. We were all dispersed across Yorkshire and usually contacted each other via telephone. One member was in Scarborough which was, coincidentally, where my birth parents were. That member asked for my birth father's name and on giving this to him he said that he could take me to his door immediately. I also found the hair salon in which my birth mother worked and it turned out that, when I had been working for ID Aromatics, I had been supplying oils, in bottles with my handwriting on, to her workplace for many years. My encounters with this support group were wholly positive.

Hepatitis B

22. **Exhibit WITN3572010** is a copy of a test result dated 20th July 1983 which states "*Test for anti-HBs by radioimmunoassay – NEGATIVE. Non-immune to hepatitis B virus*".

23. My mum asked the medical professionals to vaccinate me against Hepatitis B as she had read something about this in one of her medical journals. My mum passed away in 2016 but I discussed this with her prior to her passing.

24. **Exhibit WITN3572011** is a copy of a test result dated 6th March 1985 which states "*Test for anti-HBs by radioimmunoassay-POSITIVE. Regard as immune to hepatitis B virus*".

25. My recollection is that I was re-tested at SJH, sometime between the ages of 28 and 32, to check my Hepatitis B immunity which had dropped so I was given a Hepatitis B booster vaccination.

HIV

26. When I was aged 13 I was tested for HTLV-III. The date of the report was 18th April 1985 and the results stated "*Radioimmunoassay test for HTLV-III: Negative*". This is attached as **Exhibit WITN3572012.**

27. This test took place in the Adult Haemophilia Centre in SJH and prior to the test, I overheard the Haemophilia Nurse called GRO-D, telling another medical professional that I had been given the same batches as some male Haemophiliac patients, five of whom had become infected (with HTLV-III). After this test, my blood samples were sent to London for testing and within 2 weeks I was given the negative result. This was one of the longest 2 weeks of my life. I was told not to discuss the test with anyone whilst I was waiting for the results and I remember really wanting to tell my friend but I refrained from so doing. I would like to query why it took 12 months to tell me about my Hepatitis C test result whereas only 2 weeks to tell me about my HIV test

result despite the fact that this also involved the samples being sent to London.

Section 3. Other Infections

28. **Exhibit WITN3572013** is a copy of an extract from my medical records entitled "*Confidential Patient vCJD Exposure Assessment Form*". The document is not dated and records the fact that I am at risk of VCJD for Public Health Purposes.

29. The NHS produced three different letters in relation to vCJD which depicted three different risk/no risk scenarios. SJH erroneously sent me all three letters and the most serious one happened to be on the top; which reflected the fact that I had received blood products from a donor who had gone on to die of vCJD. When I received the above communication I started crying and telephoned my mum in tears. I thought "*here we go again*". I was utterly distraught and very worried. This was another trauma in itself that I had to deal with. I was being seen at both SJH and RHH at that time so I telephoned RHH and they confirmed that SJH had got it wrong and that I was on the ordinary "*at risk*" register.

30. I request that the Inquiry investigate the matter of VCJD in more depth. Further research should be conducted into how quickly VCJD can develop as little is known about this at present. I understand that a proportion of the general public will, in any event, show VCJD symptoms after many years. I watched a documentary on the BBC which focused on a cannibalistic tribe in Papua New Guinea who ate their ancestors. It was discovered that the disease was commonly found in that society. More should be done to support these studies and to find a method of quantifying the level of risk we are all facing.

31. Furthermore, in the latter part of the 1980s, Richard Lacey, Professor of Biomedical Sciences at the University of Leeds, suggested that there were links between the cattle disease BSE, scrapie in sheep and its human variant,

VCJD. He was ridiculed for this by the Government; however I think his hypotheses should have been considered further.

32. I still worry about the risk of VCJD today. I am potentially at risk of this every time I treat myself and there is no diagnostic test for the same. I had memory problems in my late 20s and was very paranoid about this and thought *"is this the start of the end"*? As far as I am aware, it was my depression but the worry is still there for the future.

Section 4. Consent

33. I believe I was tested and treated without my knowledge and certainly without being given full information about matters. I was therefore tested and treated without my consent.

34. I do not know if I was used for the purposes of research, however, I extrapolate that this must be the case. When I was given Factor VIII concentrate for my elbow bleed, it was not a life threatening situation that necessitated such a risky treatment regime. In my view, the amount of treatment I received was unnecessary. I was treated twice per day over a number of days and it was a horrendous experience. The medical professionals advised that such a regime was necessary to regain full control. I am of the opinion that I was a Previously Untreated Patient (PUP) and that they were carrying out research on me. I was aged only 12 and was on the adult haematology ward in a side room. I was subject to highly inappropriate, verging on abusive, behaviour on the part of the medical professionals.

Section 5. Impact of the Infection

35. For the majority of my adult life, in terms of physical impact, I have battled against chronic fatigue which has interfered with every aspect of my life. Even if a bomb had been placed underneath my bed, I would at times have been unable to move. I cannot comprehend why the medical professionals

had not suspected Hepatitis C sooner. I had gone to the GP complaining about Hepatic type symptoms such as sleeping excessively, sometimes for up to 17 hours a day. I was also complaining of lethargy, exhaustion, Irritable Bowel Syndrome (IBS) and an allergy to wheat which commonly occur with liver problems. My GP, who I was not particularly impressed with, firstly attributed my symptoms to anaemia and then diabetes. I am at a loss to understand why they did not thoroughly investigate my symptomatology sooner.

36. Eventually, my GP referred me to a Hepatologist and I believe that this was about 6 years ago. He said "*let's be on the safe side and go to Hepatology*" and I said "*why*" and he replied "*well your LFTs have been abnormally high for the last 10 years*". I was extremely shocked as I had been going to the GP since my mid to late 20s yet I was not referred until the age of around 42. I now have cirrhosis through no fault of my own and have to deal with a multitude of additional problems and symptoms in this regard.

37. This is just one example of being let down by the medical professionals. I have been let down at every juncture and been constantly undermined and told that I was making too much fuss. This was so far from the truth and the reality was that I have been very sick for the last 20 years when I had been visiting my GP and complaining of liver related symptoms. I suffered similar issues when I complained about my blood sugars and advised that the smell of my urine had completely changed. I was ignored for around 6 years in relation to this when all the GP needed to do was a Glucose Tolerance Test (GTT) or a fasting blood sugar test which would have shown that I was diabetic. Furthermore, diabetes often co-occurs with liver problems.

38. My first major downfall in my mental health began when I was tested for HIV in 1985. I suffered a mental breakdown and I cried every day, both before and after school. I began to self harm and I remember finding a chemical called which is used as an industrial solvent in my dad's garage and I started sniffing this as I wanted some sort of escapism from the reality of what I was facing as a school girl. I did this until approximately Christmas 1985.

39. I also put on a lot of weight and I often felt paranoid and depressed. I was struggling with my physical and mental health due to my heavy bleeding and chronic and acute pain.

40. When I was diagnosed with Hepatitis C I went completely off the rails for a period of about 18 months. I began bombing speed several times a week and drinking excessively. I was in a very bad place mentally and I was avoiding the medical professionals at this time. I also suffered from a brief psychotic incident which occurred after I had been out at a friend's bonfire party.

41. Over the years I have tried very hard to remain strong, stoical, as that was how I was brought up and it is how people in our country behaved which meant I had kept my feelings bottled up. However, they then exploded in the most self-destructive way imaginable. I turned to self harm again and became suicidal. When I was aged 28, I was in Edinburgh for New Year and I climbed up the scaffolding of a bridge but fell onto some more scaffolding below, which meant I could not jump off the top. When I managed to climb back down, someone had stolen my bag which I had left at the base of the scaffolding. I was staying in Edinburgh and had no door key, bank card or money as they had all been in the stolen bag. I was due back at work on the Monday and it was a massive headache on top of my already very fragile mental state.

42. I have been treated for depression for the last 20 years. Prior to this I self-funded psychotherapy sessions. When I stopped my psychotherapy sessions, the suicidal feelings quickly returned. Due to the re-emergence of the same, a good GP made an emergency referral to an NHS psychiatrist. I was initially diagnosed with depression and then this changed to bipolar disorder as I was experiencing manic episodes. My diagnosis then changed to Traits of Borderline Personality Disorder; the symptoms of which overlap almost entirely with those of Post Traumatic Stress Disorder (PTSD). The reason I make this link is because I believe that a very large number of the community infected and affected by this scandal are displaying PTSD

symptoms following the trauma they have all experienced. I am also being treated for anxiety and medical needle phobia.

43. I also became fixated on the idea that I would die from liver cancer at the age of 32.

44. **Exhibit WITN3572014** is a copy of a letter dated 3rd March 2005 from Professor M Makris to Dr C Broom, GP, which confirms that I suffer with Menorrhagia (which means that my menstruation is life threateningly heavy and I have to use three sanitary towels together and a tampon, which I change every half an hour), Arthropathy and Depression. The letter also lists some of my current medications at that time which included Haemate P, Tranexamic acid, Norethisterone, Prostap SR, Venlafaxine, Perindopril and iron tablets. I am aware that Norethisterone (and etynodiol acetate ie Femulen which I have also been prescribed) have been reported to cause or exacerbate depression.

45. Currently I suffer from Non-Alcoholic Fatty Liver Disease, Cirrhosis of the Liver Asthma, Haemarthrosis, Depression, Generalised Anxiety Disorder (GAD), Medical Anxiety, Traits of Borderline Personality Disorder, Mood Swings, Type 2 Diabetes and Coeliac Disease, which was diagnosed approximately 7 years ago, Chronic Pain, recurrent Cellulitis and Steal Syndrome in my left hand.

46. In June 2019, I suffered a bout of Jaundice and in July 2019, my GP told me that I had a Decompensated Liver and referred me back to the Cirrhosis Clinic for follow up. I attended in August 2019 and it was confirmed that I had had Jaundice since June and that I had Hepatic Encephalopathy. In relation to my liver, I now have 6 monthly check-ups and ultra sounds and yearly Fibro Scans.

47. I was taken into the Accident & Emergency Department at SJH by ambulance in November 2019 with breathing problems which turned out to be Pneumonia, Pulmonary Oedema, Ascites and an Oedema of the legs which

they believe was caused by my liver problems. I had a torrid time because I was initially discharged after only 5 ½ hours because they failed to identify the serious nature of my problems. I was put on diuretics to remove the fluid from my abdomen and I was coughing up blood and pus so telephoned my GP who treated me for pneumonia which kicked off the jaundice and Hepatic Encephalopathy again.

48. I never received any treatment for Hepatitis C and spontaneously self-cleared the virus. I found this out when I turned 28. There was a time lapse between my Hepatitis C antibody positive test results and when I was told I had self cleared. I suspect it was because they were waiting for the introduction of the PCR tests.

49. I believe that the medical professionals would have offered me treatment for my Hepatitis C and it is correct that they wanted to carry out a liver biopsy on me to determine the actual state of my liver. However, given that they were unable to control my massively heavy and prolonged periods there was no way that I was going to let them conduct a biopsy. One of my friends, GRO-C GRO-C, who has the same diagnosis as me Von Willebrand's Type 3, had a liver biopsy done and she ended up in intensive care and was not expected to survive, due to severe bleeding. Thankfully she pulled through.

50. My mental health has really suffered over the years due to a combination of factors to include the constant worry in terms of my private life. When I found out that I had Hepatitis C, despite the fact that I was not given any advice or information regarding the risk of transmission, I was immediately worried that I had passed the infection to my partner at the time. We had stopped using condoms and I was on the contraceptive pill. Furthermore, due to my VWD I often bled during sex which meant that there was often blood contact. As soon as I found out about the virus, we started practising safe sex.

51. Hepatitis C and VWD have robbed me of my chance to have children. I was deterred from the chance of having my own children and I would have liked to start my own family. There were so many nails in the coffin. If I stopped taking the contraceptive pill there was a real risk that I could bleed to death. I

was devastated and I remember going to see my friends and crying about the fact that I could not have children. I was a complete mess and it was such a sad and difficult time for me.

52. Over the years I have struggled with depression which made it very difficult to socialise and this was exacerbated by the fact that I was working full time and would spend the rest of the time sleeping due to my chronic exhaustion and lethargy caused by the Hepatitis C. On a weekend I would sometimes need to sleep for 20 hours in a 24 hour period. Following the breakdown of my relationship with my partner at the time, I became even more lonely and isolated.

53. When I look back at how my life has been I realise that I struggled for so long. Life became very hard and a real drudgery. I was trying to hold down a job, pay the bills and deal with chronic fatigue and pain. I was mentally and physically exhausted and I had not had a day off or a holiday for over a decade. I struggled for money and my periods were so heavy that I spent a proportion of my income on sanitary protection. Sometimes I was so exhausted and broke that I would just eat some bread with a pot noodle in bed.

54. I was in a situation where I had no partner to turn to for support. I was always tired after work and never had the will or energy to venture out of the house after work or to cook fresh food. How else could you socialise or interact with humans if you could not go out of the house? I was left alone with my thoughts for the most part which was extremely unhealthy. Thankfully I met my new partner in 2008 and was with him until his death on 28th November 2017. He was a huge support to me and would take me to appointments and was always wiling to help out. He worked full time but his employer afforded him flexibility.

55. I did not make my infection common knowledge as I knew of the stigma surrounding these infections. I did tell my boss at GRO-D and I was repaid in a horrid way. A few days after my disclosure, I came into the office

and my male boss was on the telephone to his sister asking her about the risks of transmission pertaining to Hepatitis C. This felt like being shit on from another level. Rather than speaking directly to me, he allowed me to overhear this. Following this, he told me that if I had a nosebleed I would have to deal with it alone with rubber gloves and then empty the bin. He became really paranoid about the risks of infection. Obviously I was an adult and cleared up my own nosebleed mess anyway!

56. It was not an everyday conversation to have with people. Luckily, my friends who knew were very understanding and supportive, although I only told my best friend in 2018, about the HIV test and not being allowed to talk to anyone.

57. In terms of my family, when I told my parents, they did not react much. No one really understood the impact on me. When my mum came round to visit me she would thoroughly clean and bleach the toilet after I had used it and before she used it. This angered me because her actions made me feel dirty. Sadly, she continued to act in this way, even in her own home. However, my mum was a great support in the house because she cleaned for me until she was nearly 70 as I was unable to do this due to my complete exhaustion. I am now the recipient of a care package, which includes cleaning, following my successful Disability Living Allowance (DLA) claim.

58. Moving to my employment history, I started working full time in retail aromatherapy the day after I finished my A-Levels when I was aged 18. I remained in this role for 7 years and then I undertook various administrative roles and did a couple of years in the corporate world before embarking upon my NHS and healthcare related roles which saw me end up as a co-ordinator at NHS Leeds.

59. **Exhibit WITN3572015** is a copy of a letter dated 4th May 2001 from John W Papworth-Smith, Occupational Medical Officer to Dr McVerry which states "*This lady with Von Willebrand's Disease Type III is having significant problems with recurrent epistaxis and menorrhagia. The purpose of this letter is to inform you that the impact is of sufficient degree and duration to generate*

for her significant employment problems. This has impacted upon her mental health".

60. I was just beyond schooling age when I was told about my Hepatitis C; it was one of the things that deterred me from pursuing highter education because I thought there was no point in doing a degree so whilst I did sit my A Levels, my weekend job became my full time job. I chose to earn money and enjoy the remainder of my life.

61. After leaving ID Aromatics in 1996, I struggled with work. In my next job my working hours were long and I had to go in 6 days a week, whereas previously I used to start at 10.30am which suited me well. I struggled physically and mentally with the earlier starts of 8.30am as I was unable to get sufficient sleep.

62. To increase my skill set, I joined evening computer classes and secretarial courses. I then spent one year temping. I started as a basic administrator working mainly on data entry and filing. I then joined the banking industry working for Alliance and Leicester and the Halifax for 2 ½ years. I had to retrain for this and also had to take a pay cut whilst I developed the required skills. The Halifax offered me a permanent position but it took 3 months to obtain the requisite medical clearance. Furthermore, due to being on short term temporary contracts, I did not qualify for holiday pay, sick pay or sick leave. Following this role, I moved into the NHS where I remained for 12 ½ years.

63. Finances have been very tight over the years. Prior to me putting myself through private psychotherapy, I had accumulated a good deal of debt. I thought that I may as well enjoy life and I took out a number of credit and store cards. I then funded my private psychotherapy to the sum of circa £2,000. I also paid for taxis because I was physically and mentally exhausted and had been getting 2 buses to work and then home again and I was not eating properly. I had accumulated about £20,000 of debt over a relatively short 18 month period.

64. This was not me. I used to be so careful with my finances. Ordinarily, I spent money with caution and the only purchases I had ever made via a credit card prior to this period were a washing machine and a video recorder.

65. I suddenly found myself in a situation where I could not even afford to pay my bills or a simple bus fare. I could not afford a weekly grocery shop and relied on my mum for food. She would send me a food parcel every week which was extremely degrading for both of us.

66. Things started to improve when I started working for the NHS and when my partner started sharing the household expenses. Unfortunately after his death, our household had one less income to rely on and as stated previously, he worked full time, so I really felt the resultant financial squeeze.

67. In terms of my care, I have a carer who has been coming to me for about 11 years now and for 14 hours per week. I never used to have to fund this but following my partner's death, I now have to pay £165.10 per fortnight for this service. Needless to say it has been difficult and made my financial situation very tight.

68. My application to the Department for Work and Pensions (DWP) for DLA was prompted by Linda, who was a Haemophilia Social Worker. She was so helpful and upon hearing my situation she offered me a home visit and helped me to complete the relevant forms. Dr GRO-D on the other hand totally dismissed me in this regard when I asked him if those with VWD were eligible for DLA. He threw the British National Formulary on the floor and told me to pick it up. I did as I was told and as I handed the book to him, he told me that I would not get anything.

69. In or around 2005 I was awarded DLA. Prior to this I was never once unemployed and had had no gaps in my employment history. When I first claimed benefits, I was still working but reduced my hours to 28 per week. Eventually this reduced even further to 18 hours per week, but I still wasn't managing.

Summary of Impact

70. My negative experiences with the medical profession have led me to feeling that I have to be hypervigilant to the point of paranoid about my health issues because for so long it was up to me to gain the right treatment and to be proactive in every way because the medical profession let me down at every juncture. I have been left with the history of Hepatitis C and a bag of trauma consisting of a plethora of problems and issues flowing from this infection, as borne out in the impact section above.

Section 6. Treatment/care/support

71. When I was in full time employment, I paid for private dental healthcare. I had to stop this when I could no longer work and instead relied upon the NHS. I duly registered with my local NHS dentist and requested a clean and polish twice a year. They seemed happy to oblige but when I had not heard from them for about a year, I telephoned the practice and they told me that I was not registered with them. This happened on three separate occasions and each time I had to again complete the initial registration forms. I felt that they did not want me on their books. I discussed this with the Haemophilia Society (HS) and they told me that my experience was certainly not a unique one. They told me to speak to my Haemophilia Centre to see if I could obtain my dental care there. I therefore spoke to the Centre at RHH and they were happy to treat me at the Charles Clifford Dental Hospital.

72. No counselling or psychological support was made available to me in consequence of being infected with Hepatitis C. As previously stated, I self funded psychotherapy sessions and my GP made an emergency referral to an NHS psychiatrist but to this day I have not been offered anything as a result of being infected with Hepatitis C.

Section 7. Financial Assistance

73. Up until recently I faced several difficulties in accessing financial assistance from the Skipton Fund (SF). I sent in my application years ago attaching proof that I was Hepatitis C antibody positive. They replied asking about my BMI and requesting I send them PCR positive results, which I did not have at that time because I had not had the test. The SF was supposedly set up to help the infected and affected but they made me feel like I had to jump through hoops to prove that I had been infected. The burden of proof should not lie with those who had been infected or affected. Their behaviour was morally wrong and would certainly dissuade real victims from applying; I ended up giving up as they made you feel so worthless and I believed that they would not help me.

74. In February 2019, after the announcement of the Public Inquiry, I applied to the EIBSS, with the assistance of a Medical social worker from RHH called Sarah Bowman. I chased them in June 2019 and copied in a number of people to include Sarah Bowman, Su Gorman, Sue Threakall, Andy Evans, Liz Caroll, MP Jackie Doyle-Price and my Consultant at RHH. I got a letter back to say they were looking into it and waiting for further information. They also said that a letter had gone missing. About two weeks later, I received a lump sum of £20,000 and a letter stating that I would be paid £345 monthly.

75. Around this time one of my friends was giving me some information about the uplift in payments and some people who were members of the HS sent me the letters they had received in connection with the new uplift in payments. The letters stated that they would be paid £1,500 per month starting from July 2019.

76. I therefore wrote to the EIBSS again, and copied in the same people I referred to in paragraph 74 above, explaining that I had not received this letter of uplifts. I was permitted the payments and received my first payment on 1st July 2019. However, I did not get any response from the EIBSS the increased

amount just turned up in my bank account. I had to chase them for a breakdown and a confirmation letter of the same.

Section 8. Other Issues

77. Most Haemophiliacs discovered the existence of the financial institutions through the HS. My parents and I believed that the HS was only for Haemophiliacs. About 17 years ago my mum got in contact with the HS while I was suffering from horrendous menstruation due to my VWD. I had endured solid and heavy bleeding for circa 8 months. Their advice was to move my care from SJH to RHH which we did and that was how I got to RHH.

78. I ended up becoming a Trustee of the HS in 2014 and retired from the role following my partner's death in 2017.

79. 20 years ago, I also set up a support group called "*Women who Bleed*" which was for all women with bleeding disorders. I had found only limited information about this at the HS and felt that I was able to use my life experience to help others and raise awareness surrounding bleeding issues. I wanted to create a safe place in which to discuss taboo matters. I felt that with this support group things were definitely moving in the right direction.

Anonymity

80. I do not want to be anonymous and I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C ....

HELEN LOUISE CAMPBELL

Dated...31|1|2020....................