Witness Name: Mrs Deborah Jones
Statement No.: WITN1913001
Exhibits: WITN1913002
Dated: 9 April 2019

WITNESS STATEMENT OF MRS DEBORAH JONES
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is Deborah Jones; I like to be called Debbie. My date of birth is GRO-C GRO-C 1960. My address is known to the Inquiry.

2. I live with my daughter and her two young sons, in her house. I am classed by the Department of Work and Pensions as having no fixed abode. I moved out of my home in July 2018 for financial reasons that are related to me becoming infected with hepatitis C.

Section 2: How Infected

3. On GRO-C 1980 I delivered a healthy baby boy in St David's Hospital, Bangor North Wales. There were no complications, it was a normal delivery. I was very emotional at the time and crying a lot. Some hours later I was told by a nurse on the ward that I would be given a blood transfusion the following morning; the GRO-C 1980. She told me that I was a bit anaemic and would

be bouncing about down the ward after the transfusion. She also explained that my son would be taken off the ward during the transfusion. I became really upset at the thought of the transfusion firstly because I did not want to be separated from my son and also because I was paranoid about needles anyway. The next morning I was placed on a drip containing clear fluid and another drip containing the blood. I was attached to both for the whole of that day and into the late evening. I can remember seeing the bag of blood hanging from a metal frame it was attached to and it was pumping the blood into me. I was totally confined to my bed for the whole of that day. Throughout the whole the thing I was very distressed mostly because I did not have my son with me and I could not feed him or change him. I honestly do not know why they kept my son from me.

4. I fell pregnant with my second child in 1981; I went for ante-natal care at St Mary's Hospital in Manchester and when I went there first I had to give blood. This was standard practice. A short while later, I was called in to see a consultant who informed me that I was carrying an antibody called anti-Kell. The consultant gave me a grey cardboard card which stated that I could not be a blood donor, that I should carry it with me at all time and that I should present it to anyone in a situation where I needed blood. I had no idea what this meant and the consultant did not explain anything to me. I left the appointment confused and shocked. Much later through prompting from me; because I knew that I had received a blood transfusion and my research had told me that the only way to develop the anti-Kell antibody was through a blood transfusion, that my GP confirmed there were references to the anti-Kell antibody in my records. There was no reference to me having received a blood transfusion; it seemed all these records were not available. This GP also confirmed later, following some tests that he did, that I had contracted Hepatitis C.

5. I was not infected as a result of my relationship with another person.

6. I was not given any information or advice about the risk that I may be exposed

to prior to the blood transfusion. I know this because if I had been given this information and thought there was any kind of risk, I would have walked out of the hospital.

7. I was infected with Hepatitis C.

8. I was diagnosed with Hepatitis C virus on the 5 October 2015 by my GP. Initially he was concerned about my liver function tests following a diagnosis of gout from a routine blood test. My liver function came back as being high so he wanted to do further blood tests. These tests were carried out between June and September 2015. My liver readings remained very high. He asked me about alcoholism. He told me he was going to do a Hepatitis C antibody test. I did not know what this was. I did not know what Hepatitis was. This test came back as positive.

9. I was not provided with any information; instead I was questioned about my lifestyle. I was asked whether I was involved in prostitution, I was asked whether I had ever used drugs; I was asked if I drank a lot. I was not asked whether I had received blood pre-1991. There was no mention of contaminated blood and I was unaware of everything related to Hepatitis before that point. I knew nothing about it. I asked the GP how I had got this; he told me it was a blood to blood infection, something like that. It only that I made the connection that the transfusion might be responsible.

10. I was not given adequate information to help me understand and manage the infection. I was just told I would be referred to the liver clinic in Salford Manchester and would be sent for a scan of my liver.

11. I had no awareness of Hepatitis until I was diagnosed. I actually thought it was a sexually transmitted disease. I thought it was something like gonorrhoea; my head was flooding with questions like how I have got this. I think that there should have been a public awareness campaign about Hepatitis C, had I known

that it could be transmitted through a transfusion then I might have requested a test many years before. The information should have been put into the public domain as soon as the NHS knew there was a problem. Even if I had been aware of there being a risk attached to the transfusion I received in 1980 I would have been alert to a side effect that could have been related to it.

12. The fact that the emphasis was placed on alcoholism and my lifestyle made me feel dirty and degraded. I remember leaving the surgery feeling completely humiliated. There was a complete and utter lack of information provided.

13. It was not until I attended my first appointment at Salford Liver Clinic in Manchester that I was told about the risk of others being infected but this happened after the consultant questioned me first about my lifestyle, again, and at that point because I had gathered information about it and had registered with the Hepatitis C Trust, I was able to inform him that I had received a blood transfusion in 1980 and was carrying the anti-Kell antibody and that this could be the only that you had become infected. He backed me up with that. He agreed with what I said. He recommended that I should have my family tested and to notify ex-partners about the diagnosis. He told me I should let them know. He did not explain what the risk of cross infection might be so I had to research it.

Section 3: Other infections

14. I believe that the anti-Kell antibody developed as a reaction to the blood that was transfused to me in 1980; it is only possible to get it through a blood transfusion or throughout pregnancy or childbirth. I received it from the St David's Hospital in North Wales in 1980 as indicated above when I was given the blood transfusions for the slight anaemia that I had following the birth of my first child. While the anti-Kell is not technically an infection, it has had a significant impact on my life and it is a separate thing to the hepatitis C. The anti-Kell served to prove the fact that I had a transfusion when my records were

missing this vital piece of evidence. The anti-Kell had a big impact on my life and defined me from the moment I was told at the anti-natal clinic in 1981 that I had it. Not only was it a risk for me; if I ever required a blood transfusion in the future, any transfusion had to contain the anti-Kell otherwise my body would reject it and the blood would attack my organs. Having the antibody demanded that I gave blood on a regular basis, but only during my pregnancies to stock pile in case I needed it during childbirth. They had to keep a reserve for my deliveries. There was also a significant risk of death throughout pregnancy and on childbirth to my children. My pregnancies from 1981 onwards were monitored very closely. The objective was to prevent the transfer of the antibody to my future children. It was almost like my blood group had changed. I was never given very much information about it. I recall being at the clinic once while pregnant with my third child in around 1995, I was giving blood at the time and the nurse said "oh I see you have the anti-Kell antibody", I told her yes, but that I did not know anything about it. She told me that it was very rare and that she had it herself and that it had come from a blood transfusion and I said to her that it was my belief that this was the way it had been given to me. There is no risk other than through childbirth of me infecting someone with it. I was always cautious when I went on holiday just in case anything happened because of the risk to my life. Luckily my children do not have it. I have questioned many times in the years since finding out in 2015 that I had contracted the hepatitis C virus (in 1980 through the transfusion I received), why the fact that I had hepatitis C was never picked up despite the fact that I had donated blood regularly throughout three pregnancies spanning the years 1981 to 1991.

Section 4: Consent

15. I do not believe I was treated or tested without my knowledge, without my consent or for the purposes of research but I do believe that I was treated without being given adequate or full information as I knew nothing about the risk of receiving a blood transfusion.

Section 5: Impact

16. The impact of being infected with hepatitis C has been huge.

17. The mental and the physical effects have been enormous: from my memory I think that the hepatitis C symptoms started in around 2005. To start with, my memory was as sharp as it once was. It was not forgetfulness that I experienced, but I noticed that I began to be unable to keep up with certain things that I used to be able to do very easily. I had to use stick-it notes to prompt me to do normal daily things, like putting orders in. I put it down to my age and overwork. I was then diagnosed with hypertension in around 2005 and I kept having bouts of depression which I initially thought was caused by the work and the pressures of running the business. I was given treatment for it in the beginning but I decided to come off it as I am anti-medication and I wanted to try to do without. I eventually gave up running the business in 2014 as I could not physically cope. My family had seen a big deterioration in me and had recommended that I do it. I planned to take six months out to rest and to see how I felt afterwards with a view to potentially going back to work, but this made no difference. The tiredness got worse. If I did anything around the house or if I went to the shops I was exhausted. This meant I could not do anything for the rest of the day. I was becoming more depressed because I could not understand why there was no improvement in my physical self and because I had to stay in at home so much. I started to experience panic attacks. I started to put my depression down to the fact that I was no longer working. I wanted to go back to work but I knew I could not hold down a job because of my fatigue. It was like a Catch-22 situation. I am run down most of the time now, I have no energy and suffer aching flu-like symptoms most of the time. I seem to pick up any virus or cold going around which can take months to clear. I feel like my batteries are constantly. I have been diagnosed with chronic fatigue.

18. My GP has told me that the most likely cause of my inability to remember daily tasks; which I call vagueness, is brain fog. I was diagnosed with Cardio Obstructive Pulmonary Disease (COPD) in 2016 I am not sure whether this is related to the hepatitis C but I think that it might be. I was diagnosed with gout in around July 2015. I have also been diagnosed with depression and obviously as I have mentioned before, hypertension.

19. I have not been given any treatment for hepatitis C.

20. I was diagnosed in 2015. There was no treatment offered to me from 2015 to 2018. I was told that there was no treatment suitable for me at that time. They said it was because I was hepatitis C genotype 3. They said that the treatments that were out there at that time would not be suitable to treat me. At the end of 2017, I was told that a new treatment had become available and it was called Mavyret and the Consultant made an appointment for me to attend the hospital in Leeds in January 2018. In January 2018, I was very sick. I was taken to bed for five weeks and I could not attend the appointment. I attended a replacement appointment in around June 2018 and saw a different consultant. I explained to the Consultant that I was too unwell to undergo the treatment at that time. I explained that I had been suffering very badly with depression as I had just lost my home through financial problems and I did not think that I could cope with the treatment particularly because my new living circumstances mean that I share a bedroom with my five year old grandson. The Consultant understood and told me that there was no pressure. She gave me a couple of months to try to see if I improved. I had another appointment in November 2018. I saw the Lead Consultant at that appointment and it was a terrible experience. He was horrible to me. I actually went into the toilets at the time and cried. There was no compassion. He said I had to get onto the treatment and I was making excuses not to go on it. I was upset because he did not understand how depressed and emotional I was. My living conditions had not changed and I was still very depressed. I could not see how I could

undergo the treatment, particularly because my living circumstances had not changed. The stress of my living circumstances is affecting my ability to have the treatment. I am stuck in this situation for the foreseeable future, until things change. The Lead Consultant asked me when I thought I could go on the treatment, I asked if we could see how we go over the next few months and I am due to see him in March; however the appointment has not arrived yet. I asked whether my liver condition had deteriorated and that this point I had not had a scan for twelve months and he told me that he could tell by the whites of my eyes that my liver was fine. I was expecting to have a scan at the time but he had no intentions of doing that, they just took my blood. I do not understand why he is pushing me to have the treatment if he thinks I am fine. The impression I get is that there is a "get her treated attitude". He actually said to me at one point, "get you treated and we can tick the box". This situation is ongoing and causing me a great deal of anxiety and stress.

21. From the research that I have done, I feel quite lucky to have escaped the interferon and ribavirin treatments. As I have said, the last scan I had was at Leeds in 2017 and I was told by the consultants then that I was very well and more likely to die from COPD than my liver malfunctioning. I did see a report of the scan which said that I had "*insignificant scarring*". This was before the treatment was offered to me. I have no idea what my current condition is or why the treatment has been offered since but I think it has to with the fact that the Mavyret is a treatment specifically for genotype 3 and I think that they want to test my response to it. I think that the long term side effects of that treatment are not established yet.

22. As I have not received treatment yet I am unable to answer this question.

23. I was unaware of my infected status until 2015; this meant that I was not able to share this information with anyone or anybody giving my treatment for another condition. I have not had treatment since this time. I did have a lumpectomy in 2002 and have often wondered whether my records would have shown my

infected status and also whether it is standard practice to test someone for hepatitis C and HIV.

24. There has been an impact on my private, family and social life.

25. Regarding my private life, I was in a relationship for approximately five years before and up to being diagnosed. When I was diagnosed the relationship ended within one week. I have not been in a relationship since. I have been and remain single. I cannot envisage meeting someone else now and having to tell that person that I have hepatitis C. I find people of my generation to be ignorant to this infection. Younger people do not seem to be.

26. I do not go out any more myself. The only time I go out is if there is a family occasion. My friends have stopped asking me to go out with them because I have always said no. I don't have a private or social life.

27. The impact on my family has been massive, mostly because of the changes they have seen in me. I used to be a very outgoing bubbly, social person. They say to me all the time now, mum you're not going out, you need to go out. It caused a lot of anxiety when I was first diagnosed because none of us understood what the virus was. There was no understanding of what the virus was. I was absolutely horrified to think that I could have infected my children and this caused me a great amount of anguish for a very long time. GRO-C GRO-C GRO-C There has also been an impact on my grandchildren, especially as I live with them. I am very paranoid as cuts and grazes. I keep tweezers, razors and all such things locked away. I carry plasters with me all the time. The knowledge of knowing has made me paranoid about things like that. My children have seen the difference in me, with mood swings when I was crying all the time in the beginning. I think they felt pretty helpless. GRO-C I had to notify my ex-husband and long term ex-partner who were both remarried and had children,

that I had been infected with hepatitis C. This did not go down well. Their partners talked about me.

28. There has been an impact on me and my family of the stigma associated with the hepatitis C.

29. The most poignant part about this was the relationship I had with my ex-partner. He was a widow with two children, we did not live together but we spent a lot of time together and supported each other through life. When I was diagnosed, he was the first person that I told. He and I were very ignorant towards the virus. When I was diagnosed I was never told that a blood transfusion could be the reason for contracting the virus. All the emphasis was on lifestyle. He thought that I had been sleeping around; he was furious and said that I could have infected his children. I was so shocked by his attitude towards me that I decided I could not see him anymore. He was never going to be supportive.

30. When I was diagnosed, I lived in a small village. This ex-partner went around the village telling people about me. I became really paranoid. This had a massive impact on me. I felt that people were talking about me and judging me. I stopped going to local shops. I used to send my daughter out to do the shopping for me.

31. My son and his partner went to a wedding. The bride and groom had two small children. My son had given their children a little kiss at the wedding. The groom called my son to ask him whether in doing that he could have passed down the hepatitis C to them from me.

32. There were no educational effects to me being infected with hepatitis C but there have been significant work related and financial effects.

33. I was a landlady at a pub and had a lease on a particular pub. I had this lease

for three years and at the point of the renewal, I decided that I could no longer continue with it. My chronic fatigue, depression and brain fog were preventing me from doing my job properly. I gave up the lease at the end of 2014. As I have explained, I planned to have six months off, to use the time to revitalise myself. However, when the six months came to an end, I was no better. I had to go on Employment Support Allowance (ESA). I was looking for work and concerned about my physical self. At the time, my mum needed a carer, so we decided that perhaps we could work it between us that I would become her registered carer. I did this from 2015 until she passed away in 2017. I received carer's allowance which was topped up with income support during this time. Afterwards, I had to go back on ESA and mostly because of my depression. I was on the ESA for around three months and it was stopped because they said that I did not score enough points. They told me that there had to be a gap of six months before I could reapply. I had a little bit of money left from Skipton which I used to live. I applied to go back on ESA and attended a face-to-face interview. I was placed back on it and remain on it.

34. The financial effects started when I had to give up the pub. I had a small amount of money to see me through the six months. After that I was dependent on the benefits system. This continued up until I received the £20,000 Skipton lump sum payment in March 2016 which I used to move out of the village. I desperately needed to do this to make a fresh start. I moved to West Yorkshire to be near my son and daughter. I got myself a little apartment and furnished it. I found myself in a happier place. I was able to run my car. As the money dwindled away I was back living on benefits. I have not been able to go on holiday or to take my grandchildren for days out; I cannot run my car any more. I rely on public transport now. My dad GRO-C GRO-C and I cannot see him as frequently as I should. I have had to use a food bank. This is when my family became so concerned about me because they had not realised how skint I was. They started to help with the shopping and my son paid some utility bills. We met and discussed whether I should move in with my daughter. This was agreed. I moved out of the apartment in

2018 because I could no longer afford to live here. This has had an enormous emotional impact on me and one which I struggle with every day.

35. The hepatitis C ended my relationship. I have not had one since. The hepatitis C has affected all of my family, all of us. My children have been impacted by this in various ways. They have seen a significant change in me since I was diagnosed. They have noticed that I have not been able to be there for them. I cannot help them out anymore. I cannot help with collecting my eldest grandson from school anymore. I am just not able. GRO-C GRO-C GRO-C My children's partners must have been very concerned for their families too. My mum and dad were devastated when they found out about my virus, mum mum was unwell anyway and she felt helpless seeing me so depressed and crying all the time. She passed away in 2017. My dad is unwell now GRO-C and I feel terribly that I cannot visit him more often. I am unable to because of my health and my finances.

Section 6: Treatment/Care/Support

36. When I was diagnosed in 2015 I was told by the consultant in Salford Hospital that there were no treatments available for me. When I was move to West Yorkshire I transferred to Leeds Hospital and was told that there was no treatment available for me. This continued until I was offered Mavyret in early 2018 which as I have explained above I have not been able to receive.

37. I have never been offered counselling or psychological support. I think that this is terrible especially given how I have responded to this whole situation. My GP gave me a leaflet at one point with a number to call. I did not think that this would do anything for me; I need to have someone who understands this situation and who can help.

Section 7: Financial Assistance

38. The financial assistance I have received has been through Skipton, WIBSS, Caxton Funds.

39. I found out about the Skipton Fund via the Hepatitis C Trust through my own research online. Nobody else pointed me to the Skipton Fund. I think it was in around December 2015.

40. I received the £20,000 lump sum ex gratia payment from Skipton on 10 March 2016. I received Stage One annual payments of £3,500 from Skipton starting 1 April 2016 to 31 March 2017. The annual payments turned into quarterly payments of £875 from 1 April 2017. On 1 July 2017 I received and additional £166.67 from Caxton which was called a discretionary top up payment and which continued until the new schemes commenced in around September 2017. At this point I was transferred to the Welsh Scheme, which only paid the quarterly payments from October 2017, they knew nothing about the discretionary top up payments and asked me to provide them with the information they needed to understand the scheme. Following a number of months of campaigning they finally relented and decided they would take these monthly discretionary top up payments on for existing claimants only; they would not allow anyone else to apply to the scheme. I have also received a respite payment of £750 on 8 August 2017 from Caxton and a one off respite payment from WIBSS on 20 June 2018 for £717*. Please see update below.

41. When I first applied to the Skipton Fund, in around the beginning of 2016, I had to prove that my infection was as a result of a blood transfusion. I completed the forms they sent out to me, but they were returned. I was asked to supply medical records as the information that I supplied was not sufficient. I spent many weeks trying to find my medical records in north Wales and was eventually told by a department in North Wales where they kept the records that they no longer existed. At this point I was going to give up as I thought I would not be able to prove my transfusion. I returned the forms with the letter

from the Welsh records department, and I included a note about the anti-Kell antibody, something that my GP had found in my notes at the surgery. There was only limited information on the note but it did state that I had the anti-Kell antibody. My GP filled in the form again and we sent the note with it to the Skipton. I did not hear from them for a while, I telephoned. They told me that they were considering my application but it had to go before a board which only met every so often and a professor had to have a look at it. I was eventually accepted in March 2016. I had to apply for each of the respite payments that I have received. I had to complete a form on both occasions and show my income and outgoings from which a decision was made.

42. The only obstacles that I encountered were in getting recognised by the Skipton that I was a victim. The only other obstacles were in relation to proving you qualified for other payments through income and expenditure analysis which I found very degrading. It was like applying for benefits and I felt like I was begging for help.

43. The preconditions were that I accepted the payment was made on an ex-gratia basis, but I don't think that I signed anything containing a condition. I cannot remember properly.

44. When WIBSS took over the Caxton payments they seemed to know nothing about the discretionary top up monthly payments that were previously being made. I campaigned very strongly to the management of WIBSS to make sure that these continued to be available not just to the 25 receiving them but to everyone that who might qualify. I had to send paperwork to WIBSS about the Caxton Foundation's discretionary top up payments and I found that WIBSS were totally oblivious to the fact that some people were already receiving discretionary top ups through Caxton. There are 249 infected and affected people registered with WIBSS. Of this total, only 25 actually receive these top up payments now. This means that the remaining 224 have no access to any further top up payments. I feel very strongly that this is wrong and should not be happening. The decision was made to not allow any new applications to

WIBSS and to close off access to the top ups completely. I continued to receive the top ups only because WIBSS decided it would honour the Caxton payments that were being previously made. As I understand it we await an announcement from WIBSS about developments in relation to this. There have also been problems in relation to their approach to Stage One and Stage Two payments more generally. Shortly after Skipton was dissolved, England introduced the Special Category Mechanism payments (SCM) to their schemes; this did not reach the boundary of Wales. Those who have been infected in Wales have been denied access to these payments, and for me, this is so, even though I am living in England and am being treated by NHS in England. I have been fighting to have the SCM Payments introduced into the Welsh scheme ever since. We (myself, Contaminated Blood Campaign [CBC] and the Contaminated Whole Blood Group [CWBG]) launched a petition which highlighted the unfairness in the payments between Stage One and Two payments and the differences between those infected in England those in Wales. There was a difference of approximately £19,000 per person. There are 109 Stage One victims in Wales living on the breadline and begging for assistance, most of these, at least 70 percent should be on Stage Two payments. This is the main reason why I am living with my daughter. I did not expect to be sharing a bedroom with my five year old grandson at the age of 58 but I cannot afford to support myself. The management of WIBSS seem to have been influenced a lot by Haemophilia Wales. When I was transferred to the Welsh Scheme and I contacted the scheme for information about payments and receipt of monies, they did not know about blood transfusion infected patients, they were only aware of blood products infected patients and in particular those connected to Haemophilia Wales, in other words they were only aware of those people who have the haemophilia condition. They were totally ignorant of the extent of the problem and had ignored not only this whole blood group of infected and affected individuals, but also those who are not part of the Haemophilia Wales charity but who may still have bleeding disorder. Mt experience showed me that when people were registering with WIBSS, they were being directed to Haemophilia Wales for support. WIBSS knew nothing about the other groups. This continued until I gave them all the details of the CWBG so a person newly registering could get information from other sources than Haemophilia. The staff was obviously not previously briefed on any of this. As I was making my enquiries regarding the SCM for WIBSS Stage One, I was always told very abruptly that these payments were not available and that WIBSS had no interest in launching the SCM to the Welsh scheme. We (CWBG, CBC and I) made a Freedom of Information request in around May or June 2018, for correspondence between Haemophilia Wales and WIBSS because of the obstacles encountered with the payments and the fact that we discovered that Haemophilia Wales was totally opposed to the SCM payments being introduced to recipients of Stage One. We wanted to know whether Haemophilia Wales was influencing the decision making process at WIBSS. We received some information towards the end of 2018 which consisted solely of emails. We found out that someone from Haemophilia Wales who was connected to the CWBG Facebook Group had screenshot information that was shared within the closed group and shared these with WIBSS, this highlighted that there was a very good relationship between the both organisations. We also found out Haemophilia Wales made a point on their Facebook website that they did not think it was a good idea for WIBSS to introduce the SCM into the Welsh scheme for Stage One infected victims and that it would be preferable to hold out for a better compensation payment once the Inquiry was finished. I am concerned about the level of control that Haemophilia Wales seems to exercise over WIBSS. In include below an extract from an email that was disclosed through the FOI request "*Hi all, I have had calls from some members who have been contacted by lawyers in England representing them at the Inquiry. We are a bit concerned; we obviously want them to stay with us for the Welsh voice. I think that there will be more confusion again when the Public Inquiry starts with media coverage etc. Can I suggest that if anyone contacts your office looking for information on the Inquiry etc. that you give them my telephone number or our lawyers as they now have a dedicated line? We have a meeting on July 18th by which time we think the terms of reference will be announced and the Inquiry will then start.*" To me this is wrong. It shows the level of the relationship with WIBSS. We made another request about three weeks ago for information from WIBSS and someone within the Welsh Health and Social Care Board because we are concerned about the relationship that there is. I have had some people contact me to say that they have been treated very badly by WIBSS and the staff within the Welsh government. I understand that staff within the Welsh government has been very rude and made recipients feel dreadful about asking for help or information. Recently, when people have phoned up about SCM and discretionary top ups, they have been passed directly onto the Health and Social Care department of the Welsh Government. We received a call three weeks ago from the manager of WIBSS to say that the Welsh government had decided that it was going to introduce a form of the SCM payments which would not be like the English structure nor as easy as the Scottish system to access as it was open to abuse. These exact words were used in the conversation. The Welsh government is due to make an announcement on the day of the Cardiff Inquiry meetings on 7 March 2019. I have provided 6 pages of what I believe to be important documents that have been disclosed through the FOI process last year. They show a close relationship between Haemophilia Wales and WIBSS and disclosure of information about individuals between them, in my view this should not be happening. I have tried to reduce the amount of reading the Inquiry has to do by only selecting the key documents from this disclosure but if the Inquiry would like all of the documentation, then I am happy to provide it, should that be helpful. Please see **[WITN1913002]**.

Section 8: Other Issues

45. I would like the Inquiry to consider the information that I have included above about the relationship between WIBSS and Haemophilia Wales alongside the Exhibits I have included and to consider there is anything that it can do quickly to address this unfairness. I would also like the Inquiry to consider the obstacles that we have been facing with the Welsh Government more broadly and particularly in relation to the petition that we launched back in July/ August

2018 for the government to recognise the differences in the payment structure between the English, Scottish and Welsh schemes. It seems that they are dragging their heels as much as they can and putting off a decision for as long as they can. I have concerns about the announcement that the Welsh government says it is going to make on 7 March 2019 about the SCM, even now I wonder whether they will backdate the SCM money to last year, or whether they will not, dragging it out purposely to save money at our expense.

46. I hope that the Inquiry will ensure that this never ever happens again. I would like justice to be done, it has to be done. The Inquiry is so important, to make sure that it brings people to justice; people who knew what was going on, if it is proved.

47. I have set out above the concerns that the CWBG and I have about the relationship that there is between Haemophilia Wales and WIBSS. I believe that they are not being candid or transparent. I also think that they have been withholding information. I have found it difficult to believe in the truth of what they say relating to dates of announcements and decisions because they have not kept to these in the past.

48. I have had difficulties in obtaining access to my medical records; there are two years of my medical history that is just gone. There is a gap. I have medical records from pre-1980 and records post-1981. My transfusion was in 1980! The nurse at my GP surgery has repeatedly said that she cannot believe why there is a gap. There is nothing there, there is a complete blank.

49. I have felt that I have been pressurised to take treatment by the lead consultant at the liver clinic at Leeds General Hospital. He does not seem to have any interest in me whatsoever apart from me going on treatment. I have not had a scan done since May last year. I am waiting on an appointment.

50. This is an update for the Inquiry in relation to the announcement that was

awaited from the Welsh government in relation to the SCM payments only; the decision for the discretionary top-ups is still awaited. The Welsh Government has allowed people to apply on a self-assessment basis for SCM payments. From my point of view, my SCM application was approved and I have now received the back payments. *My annual payments will now increase from 1 April 2019, to £18,833 per annum. I have also received a back payment of £13,878 which equates to £18,500 minus £4,622 and is based on 2018 rates for hepatitis C Stages 1 and 2. I should receive my first quarterly payment on the 20 April 2019 and on the 20th of each quarter thereafter. I am hugely relieved by this as it means I can now find somewhere to live.

Statement of Truth

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

Signed: GRO-C

Full Name: Deborah Jones.

Date: 9.04.2019