

**Witness name: Mavis Beautridge**

**Statement No: WITN1829001**

**Exhibits: WITN1829002-8**

**Dated: 6 March 2019**

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF MAVIS BEAURIDGE**

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**I, Mavis Beautridge, will say as follows: -**

#### **Section 1: Introduction**

1. My name is Mavis Beautridge, although I am known to my friends and family as "May". My date of birth is  1950 and my address is known to the Inquiry. I am making this statement as an infected person. I was diagnosed with Hepatitis C ("HCV") in February 2004 having been infected as a result of a blood platelet transfusion (likely in approximately 1982-1983). The circumstances of my infection are explained in greater detail below.
2. I make this statement in response to the questions set out in a "Rule 9 Request" letter sent to me by the Inquiry care of my solicitors, Leigh Day. Those question headings are set out below, followed by my responses to them. Save where I state otherwise, the facts and matters set out below are within my own knowledge and are true. Where I refer to matters that are not within my own

knowledge, they are derived from the sources stated and are true to the best of my knowledge and belief.

3. I have four children (three daughters and one son), twelve grandchildren and two great-grandchildren. I divorced from my children's father many years ago and raised them as a single mother. It was not easy raising my children alone, especially in the fairly poor area we lived in. However, as a family we had strong values and I am extremely proud of my children and grandchildren, who have all turned out to be very successful in their professional careers and lives. We are a tightknit family and I am in very regular contact with all of them. I met my current partner, John, in 2003 and we are very happy together. He has stuck with me since my HCV diagnosis in early 2004. It has been difficult for our relationship, but I believe it has made us stronger.
4. I append some key supporting documents to this statement and I state their corresponding Exhibit Numbers in the body of this statement.

## **Section 2: How Infected**

5. I believe that I was infected with HCV in around 1982 or 1983. After various complications following the births of my four children and following a hysterectomy operation in 1976 (during which I bled so heavily that there was a large intra-abdominal haematoma requiring further surgery), I was diagnosed with what is known as a platelet defect. This condition means that my platelet count in my blood is normal but the platelets do not function. It is described by clinicians in my medical records as "an intrinsic Aspirin-like effect". It is a rare condition that the majority of hospitals would not routinely pick up, as far as I understand. From 1976 onwards I became under the care of Dr Williams, a consultant haematologist at Maidstone Hospital, and Professor Tuddenham and the Haemophilia Centre at the Royal Free Hospital. Because of my condition, after 1976 whenever I had surgery, I required Human Leucocyte Antigen ("HLA")

matched platelets. Either pre- or post-operatively I was routinely given platelet infusions<sup>1</sup> to prevent abnormal bleeding from surgery.

6. After I was diagnosed with a platelet, I had a number of surgeries between 1979 and 1986, all of which were accompanied by infusions, including the following:

In 1979, I had a laparotomy and an ovarian cystectomy;

In 1981, I had a diagnostic laparoscopy;

In 1982, I had an operation on my breast;

In 1983 I had a biopsy of my left breast;

In 1984, I had a breast lump excision and an operation on my perineum for descending perineum syndrome;

In 1986, I had bilateral mastectomies and subpectoral silicone breast implants.

7. It is possible that I could have contracted HCV from any one of these surgeries, given my platelet defect condition and the requirement for platelet infusions. Many of my treating clinicians record in my medical records their view that I acquired HCV through infected blood.

8. I have a suspicion that one particular infusion may have caused me to contract HCV. I had a phone call one Saturday morning in approximately February 1983 from the Royal Free Hospital asking me to come to London urgently. I was told that one of the donors of the platelets that had been given to me that February had developed Hepatitis B ("HBV"). I had a blood test then which confirmed that I did not have HBV (I exhibit a record of a letter from the Royal Free Hospital dated 18 August 1983 referring to this incident as **WITN1829002**), but I strongly suspect that there was something wrong with that blood batch in general and that is how I contracted HCV.

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<sup>1</sup> Various referred to in my medical records as infusions and transfusions but referred to hereafter as infusions.

9. In or around 2007 I requested my extract from the National Haemophilia Database in order to identify the batch numbers of the blood I had received when I was given multiple platelet transfusions. In a very unsatisfactory response dated 21 August 2007 (exhibited to this statement as **WITN1829003**), the National Haemophilia Database confirmed that “unfortunately, there is no treatment information or vCJD information linked to your record.” I have therefore not been able to identify the batch numbers of the blood that I received.
10. I do not believe that I was given any information or advice at the time of being given blood transfusions about the risks of being exposed to infection, and certainly not about HCV. In fairness to the Royal Free Hospital, my understanding is that they would not at the time have been fully knowledgeable about HCV.
11. I was diagnosed with HCV in February 2004.
12. In 2003, I was suffering from a number of symptoms that I now know to have been caused by HCV, as well as breast pains (please see, **Section 5: Impact**). In 1986 I had had a bilateral mastectomy and reconstruction (breast implants) (as set out above) under the care of Mr Brough, a consultant plastic surgeon at the Royal Free Hospital. I was concerned that my implants were causing my symptoms and needed to be checked. I paid to see Mr Brough privately at his clinic, The Consulting Suite, 82 Portland Place, London, to investigate my symptoms. He agreed that my breast implants needed to be changed and referred me as an NHS patient for an exchange of prostheses surgery as well as elevation of the right nipple/areolar complex at the Royal Free Hospital in Hampstead, London. I was due to have my breast implants removed on 4 January 2004, however this surgery was cancelled due to problems cross-matching my blood. Routine investigations revealed that my Liver Function Tests (“LFTs”) were raised and I was diagnosed with HCV following further investigations and blood tests conducted while under the care of Dr David Perry,

senior lecturer at the Royal Free Haemophilia Centre and Haemostasis Unit. As a result, my breast implant surgery was delayed.

13. I discovered that I had HCV about a week after my partner and I had decided to move in together in the same property. I received a telephone call from the hospital to give me my diagnosis. It was the sort of moment where you remember exactly where you were and what you were doing. I was sitting on the stairs in my house when I got the call. I was told over the phone by the person calling that they were sorry to tell me that I had contracted HCV through blood transfusions. I was absolutely ignorant to HCV at the time, which was a widespread problem in the early 2000s. I even remember asking, "is that serious, then?". I was told that I should attend an appointment at the Royal Free Hospital, which I did, accompanied by my daughter. At that point, it began to dawn on me how serious HCV was and how limited the options for treatment were.
14. In terms of the information that was provided to me about the infection by my clinicians and its adequacy, my overwhelming feeling is that, at the point of my diagnosis, the clinicians responsible for my care, and the medical profession more widely, were very ignorant about HCV. I felt like the profession had not taken time to understand the multiple and complex symptoms and implications of this infection, nor the treatment options. For example, I felt like a number of my symptoms, such as joint pain, foginess, feeling low and depressive feelings, and night sweats, were simply brushed under the carpet, attributed to other medical causes or not properly understood and treated. I regret to say that still today there is ignorance in some medical settings, including A&E departments, about HCV.
15. Eventually, following my requests to be seen nearer to my home in Maidstone rather than at the Royal Free Hospital, which was difficult for me to travel to, I was appointed a clinical nurse specialist based in Maidstone, GRO-D. In general, however, I was not given enough support and information to help me

understand and manage my condition. I feel that nobody was truly there to see me through my treatment or ensure that I was fine. In fact, I think that I taught myself about my condition and how to manage it through extensive research on the internet. I really was forced to just "google" my condition, because the support from medical staff was lacking. I remember sitting for days on end googling HCV to try and get somewhere. I recall that I once came across the most morbid American website, which detailed some individuals' experiences with HCV and AIDS. This left me feeling very scared and depressed. One day I came across the Hepatitis C Trust, which did have some information online. For me, though, this information was pointless. It felt to me that the advice was focused on things like healthy eating and "holistic" advice. I was looking for real, practical and medically-based assistance on how to improve my situation, which the Hepatitis C Trust in my view did not provide. My personal opinion was that it created jobs for people who were looking to jump on the bandwagon and, while they maybe had good intentions, did not give real practical assistance to people in situations like mine.

16. I was invited to attend some support groups for people with HCV, however these were of no help to me. The main reason for this is that the wider group of patients who had HCV were those suffering from HCV on what I can only describe as a "self-inflicted" basis, in the sense that they had typically contracted HCV from the use of intravenous drugs such as heroin. While I do not wish to pass comment on the morality of these choices, what this meant practically for me was that these groups were full of very difficult patients whose situations were very different from mine, as somebody who had contracted HCV without engaging in behaviour such as drug abuse. These group settings were not pleasant and for me they were an awful experience.
17. I firmly feel that my diagnosis, which was an accident in a sense as I was being investigated for another medical issue, came far too late. I do not understand why the Royal Free Hospital did not call people to be tested as part of a lookback

exercise by the time they *did* understand more about HCV and about the risks that patients given blood or blood products in that hospital might have been exposed to infection. I feel that the need to do this was even more obvious and pressing in my case given that, as I set out above, I had been called back and warned that a blood donor whose platelets I had received had contracted HBV. That would have been very helpful as, by the time I was diagnosed with HCV, I had been infected for about twenty years. HCV is well-known as a "silent killer" and therefore each year passing is hugely damaging in terms of the prognosis.

18. In terms of the information that I was given about the risks of others being infected as a result of my HCV, I was only really told that transmission is caused by blood to blood contact, and I predominantly had to conduct my own research on the risks of transmission to others.

### **Section 3: Other Infections**

19. I do not believe that I was given any infection other than HCV as a result of being given infected blood. However, I would like to add that I recall that there was a certain delay before I was tested for HIV following my HCV diagnosis. I have seen from my medical records that my clinician, Dr Bird, who oversaw my first course of treatment for HCV was querying my HBV and HIV status in April 2004. I can see from my medical records (letter from Maidstone Hospital dated 8 November 1985, exhibited as **WITN1829004**) that on 9 October 1985 I was tested for the antibody to the AIDS virus, which was not detected. This letter also states that I did not have the hepatitis B antigen, and both the cytomegalus and toxoplasma titres were low. This letter continues, "*There is thus no evidence that she has been affected in the past by platelet transfusions, and now that all donor units are tested for the AIDS virus there should be no risk of this in the future.*"

20. On 3 December 1997, I was sent a letter from the Royal Free Haemophilia Centre informing me that a precautionary measure had been taken to twice recall BPL Factor VIII batches because it had been found that "a donor had not met the current health requirements for CJD". The letter, which I exhibit to this statement as **WITN1829005**, stated that according to the Centre's records, I had never been treated with these batches.

#### **Section 4: Consent**

21. I believe that I did not give my informed consent for whichever blood transfusion, either in 1982-83 or otherwise, was the cause of my infection. I was not made aware at any point of the material risks of the transfusion or that the blood might be infected, including with HCV. I certainly would have attached great significance to the risks if I had known of them, I believe. I was not informed at any point if there was any reasonable alternative course of treatment, if indeed there was one.
22. I do recall, however, that around the 1980s the issue of AIDS became a major concern among the general public. I do recall that when this issue came to light, I began to be scared somewhat about contracting HIV, but I do not remember ever worrying when I was given blood. Because of my health condition, having surgery without these transfusions would have caused many problems (see explanation above).
23. I do not believe that I have been tested for the purposes of research or otherwise without my informed consent.

#### **Section 5: Impact**

24. My HCV symptoms and my HCV diagnosis have had a significant impact on my quality of life. While my children were still young, I was determined that I would get a job and I wanted to work. I started to work at a charity, which was



sponsored by Diageo, a global spirits producer and the owner of famous brands such as Baileys, Smirnoff and Guinness. The charity worked on projects based in inner city environments. I started work as a project leader and worked my way up through the company to a high-level position of contracts manager. This work involved setting up camp effectively in areas of high deprivation and conducting research into societal issues and particular groups in society with the aim of improving their situation. Examples of these groups include single mothers, women suffering from domestic violence and men in prison. I loved my job and I am also proud to say that I was very successful at it too. I enjoyed travelling around the country to manage these research projects. I was dynamic in my role and over the twelve to thirteen years I worked in this job I managed some of the best contracts.

25. It was the deterioration of my performance at work that alerted me to the fact that something was wrong with my health. In the last couple of years before I was diagnosed with HCV, I started to not feel right and to feel very lethargic. I became moodier and more emotional at work, which was completely unlike me. I prided myself on my professional attitude and objectively my performance had always been strong and praised by my employers. As I began to feel unwell, I made made some really bad mistakes at work on several occasions. It felt in this time like I had a total brain fog and could not think straight. My friends and colleagues at work began to notice this drop off in my performance and the fact that I was not meeting targets. I recall people asking me what was wrong, but I had no idea. Eventually I was assigned a manager to oversee my performance, which was a horrible and humiliating experience given my history of success at work. I have often wondered if my employers were acting correctly by taking this action given that I appeared to be unwell. Eventually, after I finished a contract in Battersea, I took a couple of months off work in an attempt to recover.

26. The dreaded call came to tell me that I had HCV in February 2004. If I had not paid to see Mr Brough regarding my breast implants, I would potentially never have discovered that I had been infected with HCV.
27. I informed work that I would not be returning for health reasons. As a result, I was never formally made redundant and therefore did not receive any kind of redundancy package. I simply left my beloved job behind. I had no other option at the time and I was in a very dark place.
28. My HCV has led to various secondary complications (as well as the side effects and secondary complications caused by treatment, which are described below). In 2007, a trans jugular biopsy indicated that I was developing non-alcoholic cirrhosis of the liver as a result of my HCV. A further biopsy in April 2011 suggesting developing cirrhosis.
29. In 2006, I was diagnosed with bilateral carpal tunnel syndrome, with a history since the late 1980s of pain in my hands, wrists and forearms, particularly nocturnal. This led to swelling in my wrists. Letters in my medical records from Dr M Batley, consultant physician and rheumatologist at the Maidstone Hospital, record that this syndrome was likely caused by my HCV, which can cause auto immune phenomena. I underwent elective bilateral carpal tunnel release surgery on 24 May 2007 under the care of Mr Goddard at the Royal Free Hospital to treat this condition.
30. In terms of treatment for my HCV, I underwent and reacted extremely badly to two 48-week courses of anti-viral therapy (Interferon/Ribavirin). Unfortunately, neither of these treatments were successful in clearing the virus. After an initial period of some months' delay after my diagnosis, my first course of treatment, which consisted of weekly subcutaneous injections of Pegylated Interferon and daily Ribavirin tablets under the care of Dr Bird at Maidstone Hospital, commenced in June 2004 and concluded in May 2005. The virus was still

detectable in my blood at the conclusion of this treatment and as a result the hospital continued to monitor my chronic HCV. I was contacted by telephone by a nurse to inform me that my treatment had been unsuccessful. Following that course of treatment, I felt isolated and struggled to get an appointment with Dr Bird, my appointments being moved multiple times meaning I would have gone two years without even seeing a consultant to discuss my condition. I therefore requested that the monitoring of my HCV be transferred to the Royal Free Hospital, where I had been a patient of the Haemophilia Centre for decades.

31. My second course of treatment, which consisted of triple therapy of Pegylated Interferon, Ribavirin and Boceprevir under the care of Professor William Rosenberg at the Royal Free Hospital, commenced in May 2013 and concluded in May 2014. The virus was again detectable in my blood at the conclusion of this treatment and a fibroscan reading conducted in September 2014 demonstrated that there had been no change in my liver fibrosis in the preceding three years. It was devastating to undergo two courses of failed anti-viral therapy.
32. I recall that when I had the very first injection of the treatment, it caused me to go into shakes and muscle spasms. Two of my daughters sat with me while the treatment took effect, which was after about four to five hours. After the initial reaction, it felt like the worst flu attack I had ever had. To undergo this harsh treatment for 48 weeks at a time, twice, as well as taking other drugs, left me completely wiped out. In those 48-week periods I could do nothing. I could not go shopping, for example, and I was totally dependent on my family. It was all I could do to Hoover about two stairs before I felt totally exhausted and could do no more.
33. I suffered severe depression as a result of the treatments and became what I can only describe as a nasty person. I am thankful and so lucky that I had such a supportive family. Indeed, one of the greatest knock-on effects of this treatment for me was the almost two years' worth of time I lost enjoying my wonderful

family and grandchildren. Although I am and have always been extremely close to all of them, involved in their lives and caring for them, during my treatment programmes I simply could not be bothered to do things because of how totally exhausted I was. This was a huge loss for me and for my children and grandchildren. I missed so much in their lives and they missed me dearly too. For example, two of my grandsons are in the Royal Marines and during one of my courses of Interferon treatment, I missed one of their passing out parades. I also missed out on my daughter and granddaughter receiving their degrees in podiatry. These should have been wonderful moments for me and my family to enjoy in life, which we were deprived of.

34. The Interferon treatment caused various other medical complications and conditions, for example it severely compromised my immune system. I suffered from anaemia, multiple recurrent urinary tract infections, sinusitis and breathing problems. This led me to feel extremely paranoid about being in certain environments out of fear I would get ill. My hair also stopped growing during the treatment. I remember that my doctor, Dr Grove, at Tunbridge Wells, was very shocked to see me. I also had serious skin problems, which meant that I itched all day, particularly on my legs. I suffered eczema all over my body and blistering rashes on the back of my hand and on other parts of my body, photos of which I exhibit to this statement as **WITN1829006**. During treatment, I had sunken eyes and was extremely fatigued. My two courses of Interferon treatment manifested as a deterioration in lung function and a tendency to asthma, which I still suffer from today.
35. Although I had the loving support of my family in this time, I felt like I completely lacked support from my medical team, who did not seem to understand the whole host of secondary symptoms that this treatment caused. In hindsight, even though I understand the treatment was approved by the National Institute for Health and Care Excellence ("NICE"), I am of the view that not enough research and testing was carried out into this harsh treatment. It felt to me that the NHS

and the relevant authorities simply panicked when they realised the scale of HCV and the number of people who needed to treatment and simply, “hit the button” without considering the full ramifications of the treatment and its effects.

36. On 23 June 2016, I commenced a third anti-viral treatment for HCV. I was treated with Harvoni and Ribavirin for 12 weeks. I completed that 12-week course on 23 September 2016 and in December 2016 my consultant, Professor Rosenberg confirmed in a letter to my GP dated 23 December 2016 that I had cleared HCV and that he now “considered [me] to be cured”. I am still under the review of Professor Rosenberg and I have had yearly repeat ultrasound scans and blood tests. My latest ultrasound scan in May 2018 showed no significant abnormality and my liver tests were in the normal range. I am due to undergo an ultrasound in May 2019. Because of my experiences with two courses of Interferon failing to treat my HCV, I cannot feel 100% confident or satisfied that this treatment has worked, despite my consultant’s prognosis. I am not aware that it is very common for people to undergo Interferon treatment twice and for it to fail both times.
37. As I explained above in Section 2, there was widespread ignorance in the medical profession about HCV and its complexities and effects at the time of my diagnosis. Living in Maidstone, outside of London where the cutting-edge medical care is, I felt this even more acutely. Regretfully, some of this ignorance still exists in the medical profession today, in my experience. I feel that, in general, after I was diagnosed with HCV I was always battling with the authorities and governmental and NHS officials to try and get the care and support I needed. It was a very lonely battle indeed and I can only describe it as always having to “fight my own corner”, never feeling like the authorities were on my side and perpetually facing ignorance about HCV. For example, I recall explaining at a job centre that I had HCV to an official working there, who replied to me, “*Oh, my mum had that*”. Of course, it was highly unlikely that that was the case and nobody seemed to understand what, or how serious, HCV was.

38. In my view this ignorance around HCV also extended to Members of Parliament (“MPs”), who I sought the help of unsuccessfully. This included Ann Widdecombe MP. More recently, I went to see my MP, Helen Grant, to talk about HCV. I was told I would receive a follow-up letter but I never did. In my view this is unacceptable and I am disappointed that, when the Inquiry was announced, MPs such as Helen Grant did not do more to seek out those infected and affected in their constituencies and support them.
39. I also had extremely negative experiences with the Department for Work and Pensions (“DWP”). The officials responsible for disability benefits had no understanding whatsoever of HCV, its symptoms or the treatments for it and their effects. As such, I never qualified for any disability benefit, despite the utterly devastating effect the two 48-week programmes of Interferon had on me. I have to ask myself, if I was not suffering from a disability in that period, when I was unable to do anything at all, then what exactly constitutes a disability?
40. For example, in December 2013, at which point I was mid-way through my second course of Interferon/Ribavirin treatment and extremely ill, I made an application for Personal Independence Payment. I did not hear a thing from the DWP for an entire year, when in December 2014 I was invited to attend a medical assessment, 20 miles away from my home. At this point, after I had begun to feel better as I had completed my treatment in April 2014, I was assessed as not eligible for any benefits. I felt so let down by this, and the fact that I had effectively been deprived any disability benefit for a year when I was so ill that I could barely move, that I wrote a letter of complaint to the Ministerial Team at the DWP (which I exhibit along with the response to this statement as **WITN1829007**)

41. My family and I have certainly been impacted by the stigma associated with a diagnosis of HCV. Since my diagnosis, there have been certain circles of people that I have always sensed have feared me. If I recall the period when AIDS came to light, I can remember there was a lot of fear and panic about whether you could catch AIDS by touching somebody or sharing a cup. Now, that sort of misconception is rarely mentioned. This was the sort of stigma that was associated with HCV when I was first diagnosed. For example, occasionally there would be somebody at work who might ask you whether they could catch HCV from you. You then begin to watch them and they begin to watch you more closely. I remember that I cut myself one day and a lady at work warned others not to come near me. This was naturally humiliating and hurtful. It took me a very long time to educate people about the risks of transmission of HCV.
42. It saddens me to say that I also feel that, when I was first diagnosed with HCV, my own children were worried about the risks of their children becoming infected. I believe this was caused by the stigma associated with HCV and the ignorance about the risks of transmission. Simple things that I had always done with my grandchildren, such as licking the top of their ice cream, or sharing a straw, became things that I felt I no longer ought to do. I do not know whether it was my children who gave off this impression or whether it was my own lack of confidence. In any event, my HCV diagnosis really affected us as a family in the beginning.
43. As I explained above, I decided after I was diagnosed with HCV that I could not continue with work. The Interferon treatment was horrendous and it made me extremely ill mentally and physically. I was certainly unable to go back to my job in that state. Eventually, after a while I decided that I could not just sit at home and I wanted to work in some capacity. I interviewed for the position of a receptionist at an Ambulatory Care Unit at Tunbridge Wells Hospital and was given the role. I did very well at my job and eventually I was asked by the ward manager to transfer to another administrative position at a higher professional

level working in the ward. I resigned from this job in 2013, as I was not able to cope with the side effects of my second course of Interferon and Ribavirin treatment. However, I still work from time to time as I am part of a bank of staff. I do not have a contract but I accept work and work a full day if I feel well.

44. Financially, my HCV has had a huge impact on my life. I worked very hard in life, coming from a reasonably poor background, to get a career that would allow me to have a mortgage and purchase my own property, to go on holidays, and to have a modest but reasonable amount of material wealth. When I had to give up my career at the charity, that had a significant financial effect. I met John just before I was diagnosed, when I was not working because I was unwell. I was starting to struggle at this point as I had no income. I was diagnosed with HCV before the Skipton Fund and the various Funds came into existence and so I did not receive any such support at that time. I believe that I was disadvantaged because of the time that I was diagnosed. I was not able to qualify for Job Seeker's Allowance because I was not fit for work. In the end I had to sell my own house and I invested the money into John's property. I have also found that as I have got older my age has been against me as over the age of 65, I was not entitled to certain benefits. Whenever I have tried to apply for benefits in the past such as disability benefit or unemployment benefit, nobody could ever understand exactly what HCV was and how it affects you.
45. The outcome was that my quality of life was severely impacted. I could not, for example, afford to run a car anymore (I had previously had a company car) and I lost my independence.
46. My financial difficulties were exacerbated by the impact my HCV had on my partner, John. John struggled to cope with my diagnosis GRO-C  
GRO-C  
GRO-C John was a self-employed plumber. Some days he GRO-C could not cope with work. I remember



[GRO-C] he did not want to leave me. As a result, we got into further financial difficulty. I remember that we wrote to our mortgage company to ask for some grace, but they gave no help whatsoever. Thankfully John is now [GRO-C] working again successfully.

#### **Section 6: Treatment/Care/Support**

47. No one-to-one counselling has ever been made available to me from the NHS or any other government organisation. The only form of counselling offered to me by the NHS was group sessions. As I explained above, these were attended primarily or exclusively by drug users and therefore this form of support was not appropriate and would not have been useful for me.
48. I would have welcomed counselling and support had it been available. In particular, I would have benefited from practical assistance. For example, it would have been very helpful to have had a support worker who could assist you with application forms for benefits and financial assistance.

#### **Section 7: Financial Assistance**

49. I originally applied for Skipton Fund payments on 22 November 2004. I have received two payments from the Skipton Fund – the stage 1 payment initially on 1 January 2005 for £20,000 and the stage 2 payment on 25 May 2007 for £25,000. I also received a one-off grant from the Caxton Foundation on 17 February 2012 for £5,228.11. Other than that, I have received no other payments from any of the Trusts or Funds.
50. I believe that I was informed that this assistance was available during a telephone call with the DWP. It was not from any medical professional.

51. I did face some difficulties and obstacles in applying for and obtaining financial assistance from the Skipton Fund. In particular, receipt of my stage 2 payment as an applicant with chronic HCV who had developed cirrhosis was delayed given the careless filling out of the application form by my clinician at the Maidstone Hospital, Dr Bird. Without even assessing me, Dr Bird wrote in the section entitled, clinical assessment, in a section where the clinician was supposed to put his or her overall clinical view as to whether the applicant is thought likely to have cirrhosis, "I think it unlikely this lady has cirrhosis". Eventually, of course, this was proven to be incorrect based on my test results. However, I am shocked that this clinician so recklessly gave this opinion without assessing me or informing me. I exhibit this application form dated 15 December 2004 to this statement as **WITN1829008**).
52. Furthermore, a little while ago I had a spell of not working at all because of back troubles. I phoned the NHS Business Services Authority, now responsible for the England Infected Blood Support Scheme, seeking assistance. However, I was entitled to nothing because the assistance was means-tested and John's income disqualified me. I cannot see how this is fair.
53. In my opinion, the level of financial assistance from the various Trusts and Funds is not adequate at all. For example, while the initial £20,000 payment seemed amazing at the time, in reality it was not even a year's worth of income for me and so it went no way at all in alleviating the financial impact that HCV had on my life. I also spent a number of years after my diagnosis during which I received nothing at all. The financial assistance was not at all adequate to reflect the real cost of HCV on my quality of life and the impact on my family.

#### **Section 8: Other Issues**

54. Since my HCV diagnosis, I have been involved in HCV awareness-raising work, including with my specialist nurse, Beverley Clark. I have given a number of

media interviews, including to BBC Radio Kent and BBC Radio London. In August 2015, I gave a television interview as part of a feature on BBC South East Today, discussing the impacts HCV had had on my private and family life<sup>2</sup>.

55. In terms of my hopes for the conduct and outcome of the Inquiry, first and foremost I would like to know if there were concerns among senior officials in the Government and the NHS that there were risks of HCV transmission from infected blood and blood products, and, if so, whether the use of these products was continued in any event. If so, I would like to know exactly which individuals were responsible and for them to be named. I would like to know if there was a cover-up by the authorities.
56. I also firmly feel that the Inquiry should recommend that those infected and affected are compensated, and that this recommendation should be implemented without question or hesitation by the Government. It is important to note that it is not simply about compensating those infected for what they have been through, but their wider families. My whole family and in particular my grandchildren were seriously affected by my HCV.
57. I also consider that the Government, the NHS and relevant authorities ought to be held to account for their failure to raise awareness of HCV. If they had done more to educate people about HCV, government officials, the general public and indeed medical professionals would probably have been less ignorant of HCV and its symptoms, as well as the devastating and debilitating effects of the treatment for HCV. This would have made it significantly easier to cope and get by, and to qualify for support and assistance.
58. I would like to highlight in this final section of my statement that I consider myself to be a very positive, tough and forward-thinking person. I am fortunate. My disposition means that despite having undergone real suffering and hardship

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<sup>2</sup> Available here: <https://www.youtube.com/watch?v=Klv8979kwck>.

because of my HCV, I am able to keep moving forward with my life. This positive way of thinking is something my children and grandchildren have been imbued with, and I believe is the root of their successes. I do, however, feel extremely sad and sorry for those who are not blessed with my outlook. It is easy to knock those who cannot get over the depression and physical impacts of HCV and move forward from their HCV diagnosis. However, I would like to emphasise that it is extremely difficult. These people need and deserve support to cope with their conditions, which they suffer from through no fault of their own.

### STATEMENT OF TRUTH

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

Signed

GRO-C

Dated: 6 March 2019