Witness Name: Rosemary Mills Statement No.: WITNW0773001 Exhibits: WITN0773002 – WITN0773006 Dated: 14 · 4 · 2019

# **INFECTED BLOOD INQUIRY**

## WRITTEN STATEMENT OF ROSEMARY MILLS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 February 2019.

I, Rosemary Mills, will say as follows: -

## Section 1. Introduction

- My name is Rosemary Mills. My date of birth is GRO-C and my address is known to the Inquiry. I have lived in Wales for 26 years. I am retired and live with my husband who still works.
- 2. I went to agricultural college and worked on farms for a few years in Cambridge but in 1978, when I had my daughter, I left to work in the administrative department at Addenbrookes Hospital. I left Cambridge when my first marriage ended in 1986, and I moved to Kent where I met my current husband. We lived on a council-rented farm and I worked in administration at Farnborough Hospital. We then moved up to Wales with my daughter when she was 16, in August of 1994. From April 1995,

I worked at Llanfyllin General Practice (GP) Surgery for 16 years, again working in administration, dealing with medical records. I was made redundant and then retired around 2011.

- 3. My daughter currently lives only a mile and a half away and has two children of her own. I regularly look after my two grandchildren.
- 4. I intend to speak about being infected with Hepatitis C (HCV) and the development of cirrhosis. In particular, I intend to speak about the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and me.
- 5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

# Section 2. How Infected

- I received a blood transfusion on 17 June 1984 at Addenbrookes Hospital in England, which was how I was infected with HCV. I was working at that hospital at the time. As I have already indicated, I worked at Addenbrookes Hospital from 1978 to 1986.
- 7. 17 June 1984 was Father's Day and I was getting dinner ready for my inlaws when I had really bad stomach cramps. I thought I needed to go to the toilet and then I had what can only be described as explosive diarrhoea that had blood in it. Previously, I had never had any issues with my bowels. An hour after that, I needed to go to the toilet again which worried me. I contacted my local general practitioner (GP) and a doctor came out to see me.
- 8. The doctor examined me. As blood had gone down the toilet, we could not tell how much blood I had lost so the doctor told me to go to the hospital for a check-up. I remember walking down the road to fetch my daughter

from the village before we all, including my husband at the time, drove to Addenbrookes Hospital. All I can remember after that was being examined in the accident and emergency department. Medical staff regularly took my blood pressure because it dropped dramatically when I stood up.

- 9. The next thing I remember was that I woke up on a ward near the nurse's station and realised that I had received a blood transfusion because I had a tube attached to each arm, one with blood in and the other with saline in. I was told that I had lost a lot of blood through a haemorrhage so they had to give me a blood transfusion. Although I was not told then, I later found out that I had also been resuscitated. They had managed to stop the bleeding somehow and I stayed in hospital until 25 June 1984, a total of 9 days. I have obtained a copy of a letter from Addenbrookes Hospital to my GP at the time. The letter states that I had lost four units of blood but there were no significant abnormalities so I was discharged and sent home. I exhibit a copy of the letter as WITN0773002.
- 10. The doctors later confirmed and told me that I had Crohn's disease<sup>1</sup> and that was the cause of the haemorrhage. On reflection I believe I developed Crohn's disease from drinking unpasteurised milk, which I was paid in when working on farms. I had a barium enema<sup>2</sup> done before I was discharged, which showed that I had an ulcerated ileum (a section of the small intestine) that was caused by Crohn's disease. In July 1984, I went into the hospital again for an ilium resection, a procedure in which the ulcerated part of my small intestine was surgically removed. I then dealt with and managed Crohn's disease through my diet. I have never been on medication for it.

<sup>&</sup>lt;sup>1</sup> Crohn's disease is an inflammatory bowel disease which causes inflammation of the digestive tract. Mayo Clinic Staff, 'Crohn's disease' (Mayo Clinic, March 8 2018) https://www.mayoclinic.org/ diseases-conditions/crohns-disease/symptoms-causes/syc-20353304 accessed 19 March 2019

<sup>&</sup>lt;sup>2</sup> A barium enema is an X-ray exam that can detect changes or abnormalities in the large intestine (colon). The procedure is also called a colon X-ray. May Clinic Staff, 'Barium enema' (Mayo Clinic, April 18 2018) https://www.mayoclinic.org/tests-procedures/barium-enema/about/pac-20393008 accessed 12 April 2019

- 11. Jumping forward to 2000, I went to my GP with symptoms I was concerned about. I cannot remember the specifics of the symptoms I was experiencing. I remember that I always used to have a rash on my stomach, legs and arms. I had tried numerous ways to remove it, including homeopathy, several different creams and ointments, and going to a dermatologist. I was always tired too. When I went to the gym I was comparing myself to others and I realised how poor my stamina was. It may have been these symptoms which led me to go to my GP at Llanfyllin GP Surgery in 2000. Again, I worked at Llanfyllin GP Surgery at the time, from 1995 to 2011.
- 12. I saw Dr Jane Rees. She looked at my medical records and noted that I had received a blood transfusion. She told me that I had been resuscitated when I went to Addenbrookes Hospital for the haemorrhage and rectal bleeding in 1984. I did not know this until she told me. Dr Rees ordered monthly liver function tests for me, which continued for four months until another doctor took over after her retirement. I believe Dr Rees was on the path to discovering I had HCV before she retired. However, I was not diagnosed for another 10 years which I explain further below.
- 13. I went to see Dr Huw Evans after Dr Rees retired. In my first appointment with Dr Evans, he circled my high ALT (alanine aminotransferase) levels on a blood test results sheet and stated that if there was anything wrong with me there would be problems with my other liver function tests, which came back as normal. As he believed there was nothing wrong, Dr Evans stopped my monthly tests at that point and reassured me that everything was normal.
- 14. About 10 years after the liver function tests were stopped, I went to a doctor other than my own because I had a lot of 'locking' in my joints. My mother had motor neurone disease so I wanted to get this checked. I went to a Registrar at Llanfyllin GP Surgery where I was still working. I decided to see a Registrar because they are junior doctors and I feel they are

trying to prove themselves so they want to make sure they get things right. The Registrar did some blood and liver function tests for me in June 2009. This was about 2 or 3 weeks before I was going to go on holiday with my sister to France. The day before we were supposed to leave, the Registrar rang me and said she had received my test results. She asked me not to drink alcohol while I was away and that if my skin colour went yellow, I should go to the doctors straight away. At one point I thought I might not go on the holiday because of it, but I did. While I was on holiday, one night I had one glass of wine, I called my husband the next day and I told him that I thought I was going to die and felt awful after drinking it. Looking back, this was because my liver could not process the alcohol. I also had extremely puffy feet, which I thought was normal in a hot country but the symptoms now tie up with cirrhosis.

- 15. For the two years leading up to that holiday, I had been becoming more intolerant to alcohol. I would have one glass of wine and sometimes my husband would have to carry me in to the house. When that happened, I put it down to menopause, as the hormones do go funny during this period, but in retrospect it was all due to the HCV causing liver damage.
- 16. When I came back from holiday, the Registrar asked that I have a HCV test but Birmingham Hospital, where the blood was tested, told her that this could not be done until I had liver tests for 6 months that showed raised results. I accordingly had liver tests done every month for 6 months. During these 6 months, the Registrar left for another practice. By this time, I realised I had to make sure her advice was followed through. I ensured that a monthly blood test was done and after the 6 months I went to another doctor and told them that I wanted a HCV test. There was no one but myself to ensure I followed it up.
- 17. Part of my job at Llanfyllin GP Surgery at this time was to process all of the lab results that came back in to the surgery. I was to put the results on the patients' notes and made sure the results were given to the correct doctor. I had access to my own results, so I could not help but look at them when

the results from Birmingham Hospital regarding my HCV test were received. Between the Christmas and New Year of 2009, my results came in to say that I was positive for HCV. The first test proved that I had once had HCV. I needed to do another test to prove that I still had it. The second test results came in January 2010, proving that I had HCV at the time. Again, I saw the results of this test in the course of my job at Llanfyllin GP Surgery. On the results sheet it stated that I needed to be referred to Shrewsbury Hospital. After that everything moved very quickly. I saw a doctor at my practice and asked them to refer me to Shrewsbury Hospital accordingly.

- 18.1 went to Shrewsbury Hospital in February 2010 and met Sandra, the HCV nurse. Sandra was incredibly supportive. She gave me her personal mobile phone number so that my husband and I could ring her if she was at home. She was, in my husband's words, an 'angel from heaven'. I was offered counselling and access to other support groups but I turned this down as I had the support from my family. The GP who referred me to Shrewsbury Hospital did not provide me with any information on HCV, the treatment or support available. I received all of this from Sandra instead.
- 19. Sandra went through all the information very thoroughly, and in hindsight, as we went through all the possible symptoms of HCV, I realised that a lot of issues I had had over the years were because of HCV rather than menopause or Crohn's disease as I had previously thought.
- 20.1 looked at my medical notes after I had been diagnosed with HCV and I could not find the piece of paper on which Dr Evans had drawn on when he noted my high ALT levels in 2000. I find that suspicious. When I was diagnosed in 2010, Dr Evans asked to see me in a meeting room where he told me that even if I had been diagnosed earlier, there would not have been a cure for the HCV. Dr Evans also made a joke, saying *"you would have had to stop drinking"* so I should have been glad that he had not diagnosed my HCV back in 2000. I asked him if he would bring up my case in a clinical meeting so that other GPs could be on the look-out for

people who had been infected with HCV, where symptoms and a diagnosis had gone unobserved for so long. He declined to do this. Dr Evans also admitted that at that time GPs were only conscious of HCV as a disease in the drug addict community, but not within those who have had blood transfusions.

#### Section 3. Other Infections

- 21.1 did not develop HIV or any other infections as a direct result of being given infected blood.
- 22. However, under 'Section 5' of my statement, I detail other conditions that I have developed as a result of HCV and cirrhosis of my liver. These include temporal arteritis and polymyalgia rheumatica.

#### Section 4. Consent

- 23.1 did not give consent for the original blood transfusion which infected me with HCV. I asked my ex-husband, once I found out about being positive for HCV, whether he had given consent or been asked to sign any forms for the blood transfusion. Although he was at the hospital when I was given the blood transfusion, he confirmed that he never gave consent on my behalf either. This may have been due to the fact that the hospital staff had to act fast and he was in the waiting room with our daughter, but I do not know for definite. Neither my ex-husband, nor I, were told at the time that I had been resuscitated. After I received the blood transfusion, I was not made aware of any risks involved including the risk of infection.
- 24.1 gave full consent for the treatment for HCV that I received. I was fully aware of the side effects of the treatment and the support given to me was exceptional. Without the HCV nurse, Sandra, it would have been a very different experience. The consultants were not approachable and Sandra was the one who gave me all of the information on HCV and the treatment.

I recently learnt that Shrewsbury Hospital has only recently had a new HCV nurse start within the past few weeks, which means that the hospital has been without one for around 8 years as I am aware Sandra retired around the end of 2011.

## Section 5. Impact

- 25. HCV affected my physical and psychological welfare. To start off with, my first thought when I found out that I had been infected through a blood transfusion was that someone had donated blood in good faith and did not realise they had HCV. Then I found out that the United Kingdom (UK) government had paid to import blood and that blood was not tested. It was a bit like finding out your father is not your biological father, I did not know who's blood I had in me. It felt like a violation, like someone had done it to me, rather than it being an accident. Once I became more aware of the actual situation I realised it could have been avoided. I became aware that the UK was importing blood that American prisoners and citizens, some of whom were alcoholics and drug addicts, had donated. These people may have been infected with HIV and HCV. That was bad enough but then the media told us that the UK government and National Health Service (NHS) had known in 1982 that the blood and blood products may have been infected, yet they continued importing the products.
- 26. Sandra asked me if I wanted to go on anti-depressants when I initially saw her, which I consented to. I started taking anti-depressants a short while before starting treatment for HCV. Throughout the first year of finding out I had HCV, I took 40mg of anti-depressants daily. I dropped down to 20mg when I stopped the HCV treatment, and I am now on 10mg per day. I still regularly go to see my GP about it to discuss my use of anti-depressants and manage it.
- 27.1 do not think that there should be a stigma attached to the ways in which a person can be infected with HCV. I believe a person should be treated without any pre-judgement. However, I am aware that when I tell people

that I had HCV, I am quick to follow it up with an explanation that I got it from a blood transfusion that the NHS administered. I do not want people to assume I was a drug addict. It is the same for the cirrhosis, I do not want people to believe I was an alcoholic. I hate that as a society we do judge people on this basis, but it is difficult to overcome this stigma.

28.1 had to tell work about the HCV and mostly there was a supportive reaction from my colleagues, apart from one practice manager, which I will explain further below. Any reaction I did get from my friends when I told them was okay. I have not lost friends or anything like that.

29. Sandra explained to me that there was a chance that I had passed HCV to

others,	GRO-C		
	GRO-C		
	GRO-C	I also had to	

checked for HIV, which I was clear of.

30. On a personal level, my husband and I had relationship issues due to HCV, which we were unaware of at the time. We found out that my liver issues could affect my libido because it affects the hormones. Before we knew that I had HCV, GRO-C

#### GRO-C

**GRO-C** In one way it was a relief because it was not in my head, it was not me, it was not our relationship that was at fault. In other ways it was a bitter realisation because we went through all that stress and frustration.

31. HCV impacts your family, and it definitely had an impact on my husband. Those who care for you worry about you more than you worry about yourself. It hurt my husband to see me suffering from the HCV, cirrhosis and the treatment.

- 32. Sandra explained to me how HCV could be passed on. It concerned me because I had had another surgery after the blood transfusion when I had been infected, the ileum resection that I have already mentioned. I could have infected other people in this way, and numerous other ways. For example, I sometimes had nose bleeds and because I was not aware of the HCV, I was not as careful as I should have been when cleaning up the blood. I had also been to have my wisdom teeth taken out and I regularly went to the dentist before I knew I had HCV. Fortunately, when I spoke to my dentist as soon as I found out that I had HCV, he told me that they treat all patients as if they have HCV, which comforted me. I found it bewildering that a dentist, who dealt with my diagnosis calmly and without drama, was more comforting than the practice manager at my own place of work. I have detailed how my practice manager reacted to my illness further below. The dentist did not judge me and never treated me differently to his other patients
- 33. Sandra explained to me that I could go on treatment for HCV for 6 or 12 months and explained that the only treatment available was Interferon and Ribavirin, which was taxing on a patient. Sandra explained that most people could not go through 12 months of the treatment so we would try 6 months and if I could, I should continue for another 6 months. I cannot fault the support I was given by her for the treatment process. Sandra explained the possible side effects, including that I may lose weight, that I may have flu-like symptoms, and that I may be extremely lethargic, among a range of other things.
- 34. Before I started the treatment, Sandra organised a liver biopsy to see if I had cirrhosis, and an endoscopy to check for varices<sup>3</sup>. I had to stay in overnight at Shrewsbury Hospital for the liver biopsy. Doctor Butterworth

<sup>&</sup>lt;sup>3</sup> Varices is abnormal, enlarged veins in the tub that connect the throat and oesophagus. It develops when normal blood flow to the liver is blocked, so the blood flows into smaller blood vessels which are not created to carry the amount of blood. This can lead to the vessels leaking blood or rupturing. Mayo Clinic Staff, 'Esophageal varices' (Mayo Clinic, February 14 2019) https:// www.mayoclinic.org/diseases-conditions/crohns-disease/symptoms-causes/syc-20353304 accessed 19 March 2019

was the consultant I was under, although I rarely saw him. I believe he was the doctor who did the liver biopsy and endoscopy.

- 35. The endoscopy revealed that I did have varices. I was surprised because I did not realise that my liver issues were that advanced. I was lucky they had never burst. The doctor banded them. Since then, two consultants have given me opposing advice if I develop varices again. One consultant has said that I should have them banded, and another has said that I should have them banded, and another has said that I should be put on blood pressure tablets. Fortunately, this is an issue I have not had to deal with again, and I hope not to.
- 36. The liver biopsy also revealed that I have cirrhosis. I was told that it was a 'grade 5 inflammation' and it was referred to as 'established cirrhosis', which is what led to the endoscopy to check for varices. They told me the stage of cirrhosis was advanced and if they did not address the HCV, I would have 2 or 3 years left to live.
- 37. When I received funds from the Skipton Fund, which I will detail further below under 'Section 7' of my statement, I spent it on a campervan for my husband and I to go travelling through Europe with if the HCV treatment did not work. I had a low life expectancy due to the cirrhosis and I wanted to spend my time living well.
- 38. Once Sandra outlined all of the treatment details and I consented to it, she got me on it very quickly. I started the treatment in March 2010 and finished the treatment in February 2011, doing the full 12 months. I did my own Interferon injections at home weekly and took Ribavirin tablets twice a day every 12 hours. At the beginning of my treatment, I saw Sandra weekly because if a patient develops severe symptoms they tend to crop up in the early days. The side effects took a while to kick in, gradually getting worse. The flu-like symptoms that were likely to transpire after every injection only came up after the first two injections I had.

- 39. The extreme lethargy started a few weeks after I started the treatment and continued until a few weeks after I finished it. I continued to work during the full 12 months of treatment but I had to change my usual working hours of 8am to 1pm, to 10am to 3pm because I struggled to get out of bed in the morning. I could not do much but work and sleep, but I did not want to let anyone down by taking time off work for a long period. I did feel a comfort in going to work because I was at a GP surgery, surrounded by doctors if anything did go wrong. Some days I was too tired for work, so with the support from managers, I did take few days off every other month. At the time I did not realise my work place was going through a restructure, deciding on who to make redundant However, the external person who came in to work this all out for the GP practice was very supportive and told me to take off any time if I needed it.
- 40. With regards to my personal life during this time, I would come home from work and fall asleep. I felt like a zombie and my husband was also working, so we had to pay someone to do the cleaning in the house. Friends helped us do a lot of the cooking as well.
- 41. I also had these moments of 'brain fog' when I could not form sentences or think of words, and my memory got worse too. The lack of concentration and ability to focus affected my job. In my role, I had to plan 6 weeks ahead but sometimes I would do things like accidentally double-book a room. As a conscientious worker I was absolutely mortified when this happened. I am under no illusion that without one of my close work colleagues, I would not have been able to get through this time at work. She helped me a lot throughout this time. It also affected my personal life, I would go food shopping and when I could not remember one thing on my list, I would come home without any shopping at all.
- 42. Prior to the treatment I did get nose bleeds, but throughout the 12 months of treatment, they were much heavier and more often. One time I had a bad nose bleed at work and the practice manager made me feel like a 'leper', telling everyone to stay away and making sure I disinfected the

whole area. It left me feeling stigmatised. A nurse had to enlighten the practice manager to the fact that she was being incredibly over the top. That was perhaps the worst reaction I have experienced as a result of the stigma associated with HCV.

- 43. The treatment also seemed to affect my eyes. I originally went to an eye specialist for a general check-up on Sandra's recommendation, but the second time I went to the specialist because I started bleeding from my eyes. The second time I went, I saw a different specialist, at Shrewsbury Hospital, who was incredibly rude and judgemental. He asked me why I had HCV and when I told him it was due to the NHS infecting me through a blood transfusion, he was much more professional and politer with me. I told Sandra and she inquired as to whether I wanted to report it, I did not. To my mind though, it does not matter why a person develops HCV, only that they need support from a medical professional.
- 44. I developed sarcoidosis<sup>4</sup>, which was a side effect of the treatment that Sandra had never heard of. It caused extreme irritation to the skin on my back, and I developed large boils which were incredibly painful. As soon as I stopped the HCV treatment, the boils completely cleared up but they have left large scars.
- 45. Throughout the treatment, I did not lose any weight and I did not lose my appetite.
- 46. Long term, I still suffer from numb toes from the treatment. I did not notice it during the treatment, which might have been because it had not started then, or because I was experiencing too many other side effects for me to notice at the time. I mentioned it to a GP at my workplace once and he confirmed that it was from the treatment, which I did not realise was a side effect, nor did I realise that side effects of the treatment could be so long lasting.

<sup>&</sup>lt;sup>4</sup> A rare condition that causes small patches of red and swollen tissue to develop in the organs of the body. It usually affects the lung and skin. NHS, 'Sarcoidosis' (NHS, August 13 2018) https://www.nhs.uk/conditions/sarcoidosis/ accessed 19 March 2019

- 47. As the treatment went on, I had blood tests taken. The HCV count was low throughout the treatment but I was not cleared of HCV until August 2011. Sandra called my mobile to tell me the news when I was cleared. I saw the consultant after that. He offered me annual endoscopies to monitor the development of varices and six-monthly ultrasounds to monitor my liver. Part of these checks included looking for cancer cells as HCV-related cirrhosis has been linked to cancer.
- 48. For the cirrhosis, I was told that because the HCV was clear it would stop attacking my liver, and if I continued to not drink alcohol my liver would remain the same, not getting any worse although it would never improve. I was also told not to smoke, which I have never done, and to limit my use of painkillers. Just after I had been given the all clear, Sandra retired too. I was incredibly fortunate to have her as my HCV nurse.
- 49. After I finished the treatment, I was made redundant. I was offered another post at Llanfyllin GP Surgery but it was different to the role I had been in for the past 16 years. I had always been involved in the administration for the nurses' rota, registering births and deaths, and processing results. The new role was for dispensing medication which I did not want to do. After the 12 months of treatment and as a result of the psychological and physical impact it had on me, I was not in the right frame of mind to learn something new.
- 50.1 also could not think of taking on a new job elsewhere. I had coped with my own job which I had done well for 16 years but another role would have been too stressful. Therefore after my redundancy, I applied for an incapacity benefit for long-term support for sickness. I was rejected after the assessment for it, because I could, for example, lift up a saucepan, walk a short distance, and lift my hand above my head. Apparently this proved to them that I was not sick.

- 51. Fortunately, I received funds from the Skipton Fund around this time which I detail under 'Section 7' of my statement below. I realised I would need to be more careful about what I spent from then on because previously I had received assistance from the Skipton Fund and did not believe I would survive to use it. The funds that I received after my HCV treatment were a lifeline because they came at the exact right time, after my redundancy and being refused an invalidity benefit.
- 52. My husband and I did have another business making fruit liqueurs, which we had started before I had been diagnosed with HCV. We used to sell it at fruit fairs and sold it to someone who shipped it out for us. I did not have the energy to make the liqueur because of the treatment, never mind the energy to go to the food fairs to sell it. Our friends supported us through this, as we had made promises and deals for orders already, we had a certain amount of product that we had to continue to make. They helped my husband make the product when I did not have the energy. We kept the business until just after the Christmas of 2011, then eventually we had to wind it up. This was another revenue stream that we lost because of the infection.
- 53.1 developed temporal arteritis<sup>5</sup> and had to go on steroids in 2015 for two years to clear it. I had been off the steroids for about two months before I started having lots of aches and pains again everywhere. It turns out that I had developed polymyalgia rheumatica<sup>6</sup> after the temporal arteritis, which is very common. I again received steroids and to combat the side effects of the steroids, I also went on anti-reflux medication. I looked up these two medical conditions, temporal arteritis and polymyalgia rheumatica, on the Internet and found they were related to HCV. Sandra had also told me that HCV could affect my muscles and strength if the liver is affected.

<sup>&</sup>lt;sup>5</sup> Temporal arteritis is where the arteries, especially those at the temples, become inflamed. NHS, 'Temporal arteritis' (NHS, November 29 2017) https://www.nhs.uk/conditions/temporal-arteritis/ accessed 19 March 2019

<sup>&</sup>lt;sup>6</sup> Polymyalgia rheumatica is a condition that causes pain, stiffness and inflammation in the muscles around the shoulders, neck and hips. NHS, 'Polymyalgia rheumatica' (NHS, January 23 2017) https://www.nhs.uk/conditions/polymyalgia-rheumatica/ accessed 19 March 2019

- 54. When I was diagnosed with polymyalgia rheumatica, I started having involuntary muscle movements in my calves. The neurologist told me that they were benign facilitations, movements of the muscles, and gave me a 6-month follow up appointment without any further medication at the time. When I went back to see him, I also had aches and pains again. He did a range of muscle tests and decided that I may have something other than polymyalgia rheumatica. For the past 6 months, I have had brain and spine tests at Wolverhampton Hospital, including incredibly painful electric shock tests that are used to check nerve conduction to see whether there has been a degeneration in my nerves over a 6-month period. I have been seeing a neurologist, Dr Bowen, at the Shrewsbury Hospital regarding these tests. I am still awaiting the results of these tests and a diagnosis.
- 55. All of these conditions that I have developed appeared to be linked to my previous HCV infection. I believe I cannot have so many different conditions, especially after I already had Crohn's disease, that are not linked to an original issue the HCV. I believe it is statistically unlikely that these new developments are not connected to my infection with HCV. When I have done research there does seem to be links between my current issues and HCV/cirrhosis. Even though my HCV infection is cleared, I am still physically affected by it and have on-going medical issues.

## Section 6. Treatment/Care/Support

56.I never faced difficulties in receiving treatment for HCV once I had finally been diagnosed. Sandra was incredibly thorough and informative. She offered counselling and anti-depressants to support me. She ensured I started on Interferon and Ribavirin as soon as possible. Within a month of seeing her I was on the treatment.

# Section 7. Financial Assistance

- 57. During my first appointment with Sandra at Shrewsbury Hospital, she told my husband and I that there was financial assistance available from the Skipton Fund. She filled in most of the forms for us. We received a lump sum of £20,000 from the Skipton Fund some time between February and March of 2010. I cannot recall the exact date but I received it before the HCV treatment started. I exhibit a letter I received from the Skipton Fund confirming that the payment was made as exhibit **WITN0773003**. As I have previously stated, my husband and I spent that money on a campervan. At that point, the only available assistance was that lump sum.
- 58. I received a second lump sum of £50,000 from the Skipton Fund because I had met certain medical criteria by developing cirrhosis. I exhibit a letter that I received from the Skipton Fund that informed me of the availability of this second lump sum payment as WITN0773004. I cannot recall when I received this letter or when I received the further lump sum payment. However, it was not long after receiving my first lump sum payment in 2010.
- 59.1 also received monthly payments from the Skipton Fund, which started at the end of my treatment for HCV. At first, the monthly payments totalled £12,800 per annum and started on 21 January 2011. Around this time, I also received a further 'top up' of £25,000. I exhibit a letter that I received from the Skipton Fund in March 2011 as **WITN0773005**. This letter details the monthly payments I started to receive in 2011 and the availability of the 'top up' payment I subsequently received from them.
- 60. When the England Infected Blood Support Scheme (EIBSS) took over, the monthly payments increased although I cannot remember to how much. I recently received a letter that again told me that my monthly payments would increase due to inflation. It has now been increased to total £18,500 per annum, starting from April 2019.

- 61.1 was also told about the Caxton Foundation by Sandra, which I then received winter fuel payments from. These payments started in 2011 and were £500 each year.
- 62.1 have had to clarify to the Skipton Fund that although I am now living in Wales, I was originally infected with HCV in England. An email that I sent to the Skipton Fund and the response I received in this regard can be found as exhibit **WITN0773006**. I am aware that in Wales the payments from Trusts and Funds such as the Skipton Fund are not as substantial when compared with England.
- 63.1 did not have any problems with the application process to both the Skipton Fund and the Caxton Foundation personally, although I have heard different from others. I did not have to provide evidence that I was infected from Addenbrookes Hospital, I only stated which hospital I had been infected in and when this had happened. There were no obstacles in accessing the lump sum payments, nor did I have problems accessing monthly payments throughout the whole process.
- 64.1 am aware that the money I have received is not compensation money because no one admitted liability. The lump sum payments from the Skipton Fund were referred to as *ex gratia* payments.
- 65. Overall, I think the Skipton Fund, Caxton Foundation and now EIBSS have been very good. They are easy to access, they have never questioned why I am applying for it, and I have not had to give evidence.
- 66.1 contacted them when I came up to retirement, as I received my NHS pension at 60, to ask whether the monthly payments and winter fuel payments would be stopped then. They confirmed that the financial assistance I was receiving was for life. I have not had another job since I was made redundant after I finished my treatment for HCV.

#### Section 8. Other Issues

- 67. My first issue with regards to what happened is that at no point did anyone get in touch with me about my possible infection with HCV, even when the government and NHS started realising that people were infected from blood transfusions and blood products. My understanding is that they are still not contacting people about their possible infection. They are not contacting people about the available financial support either. I recently met someone who was infected through infected blood and they were not aware of the financial assistance available.
- 68.1 believe the issue is rooted in that GPs were not (and are not) made aware that infection is possible from blood transfusions and blood products, as confirmed by what Dr Evans told me. I think there are few people now who may have HCV without knowing it, but it should be in the back of the minds of the NHS and respective GP practices. I think there has been a complete failing by the fact that GPs were not informed or aware about the possible risk of infection from blood transfusions and blood products.
- 69. The second issue I have is the delays within the NHS. If I had been contacted 10 years earlier to when I was told that I had HCV, I believe I would not have developed cirrhosis. Early diagnosis was possible. Due to the delay, I fear that I could have infected other people without my knowledge, it is not just my life that was at risk during all those years of infection. I do not know why I had to wait 6 months before I could have the HCV test in 2010, especially after a Registrar had specifically requested it. This added another 6 months during which I had un-treated HCV, resulting in damaging affects on my liver which could have been very easily avoided.
- 70. My third issue relates to the widespread affects of infection on others. It needs to be remembered that this is not just about the infected, it is also about the affected. On the one side, the financial assistance that I received changed my life for the better, but on the other side, HCV has ruined and changed a lot of aspects of my life. My life with my husband may have

been very different if I had not been infected with HCV, and the strain on my friends and family could have been avoided.

71. Overall, I detail the exhibits which I have referred to throughout my statement as follows:

Exhibit Reference	Document date	Description
WITN0773002	05/07/1984	Letter from Addenbrookes Hospital to GP re Rosemary Mills' blood transfusion.
WITN0773003	29/03/2010	Letter from Skipton Fund to Rosemary Mills re invoice for £20,000
WITN0773004	Unknown	Letter from Skipton Fund to Rosemary Mills re Skipton Fund ex gratia payment additional payment
WITN0773005	28/03/2011	Letter from Skipton Fund to Rosemary Mills re ex gratia payments
WITN0773006	21/01/2011	Email from Skipton Fund to Rosemary Mills re confirmation that the fund is now aware that Rosemary was infected in England

# **Statement of Truth**

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

Signed	GRO-C	
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Dated 14.4.2019