Witness Name: John Dunn McLAIN
Statement Number: WITN4116001
Exhibits: Nil
Dated: 06 / 01 / 2022

INFECTED BLOOD INQUIRY

WRITTEN WITNESS STATEMENT OF
JOHN DUNN McLAIN

I provide this statement in response to a request made under Rule 9 of the Inquiry Rules 2006, dated 4th March, 2020.

I, John Dunn McLain, will say as follows:-

Section 1 - Introduction

1. My full name is John Dunn McLain and I was born in County Durham on GRO-C 1938. I live in Wales at an address which is known to the Infected Blood Inquiry with my wife Joyce McLain (née Richardson) who was born on GRO-C 1938. At the time of my providing this statement, both Joyce and I are each approaching eighty four years of age. We are both retired from full time employment.

2. I intend to write of my wife's infection with Hepatitis C (also referred to as HcV and / or Hep' C) which we believe to have occurred in 1986, the direct result of a blood transfusion (or transfusions). In particular I shall discuss how she came to be infected, the nature of her subsequent illness(es), the treatment she has received, how being infected with HcV

has affected her, and the impact her Hep' C infection has had on her and our lives together.

3. I was brought up in County Durham where I left school having under-achieved expectations re. educational qualifications, but thereafter I worked hard both in terms of employment and by further self-educating myself. I started a marine engineering apprenticeship in a large engineering group making ships engines, commenced 'night-school,' attending four times per week to catch up, and achieved O.N.C. level within two years. I was awarded 'Apprentice of the Year' from the group's five engineering works and was sent on 'Outward Bound' courses for leadership training.

4. This was followed by being selected from all of that years' courses to take part in a Lakeland mountaineering expedition and subsequently to be a member of a seven week leadership expedition to Iceland. The group then sent me to college for three years to gain diplomas in engineering, logistics, time-and-motion techniques and man-management, by which time I was working in their main engineering design office.

5. I was a fairly self-motivated individual, encouraged by having been told that I was something of a 'born leader.' In 1960, when I was around 22 years of age, and at a time when the North East of the country, where I worked and lived, was in something of an economic depression, I managed to secure employment with an Austrian textile company as a design engineer, based just outside of the London area.

6. Thereafter, I continued working for Non-British international companies in consumer goods manufacture, production and distribution (three Swedish, one German and finally a Swedish company, a world leader in cellulose products). I was a Manufacturing Director at 32 years of age, Managing Director at 36 , and remained at that level throughout my employment. By then, I was registered as a C.Eng, MIMech E, FBIM and FI Mgt.

7. Joyce is my second wife, and I am her second husband. I was first married on 5th November 1960 , and divorced in 1975. I had been travelling all around the world on work related matters, and frequent distancing and several house moves had an adverse impact upon our relationship, and we divorced.

8. Joyce was born in Yorkshire, into a family where she had three brothers. The family were all what could be considered to have been healthy, and in particular her mother lived until one hundred and one years of age. There was, and with her exception is, no known history of any form of haemophilia or other blood disorder in her family.

9. Joyce herself had experienced no untoward health issues until she had been given blood in 1986. Joyce has never had tattoos, ear piercings, stitches (sutures), required surgery or experienced any clinical or other procedure from which her blood may have been infected. She is also a non-smoker and takes no alcoholic beverages in any form.

10. She met her first husband in 1958 and as a couple they had two children both of whom were born naturally with no complications. They divorced in the late 1960's and she has no information to suggest that her first husband may have had any form of blood disorder, or that anything like haemophilia was known within his family.

11. Joyce and I met in February, 1973. At the time she had been divorced and I was going through my divorce (which was finalised in 1975). We were together as a couple for some thirty five years before we married in 2008. At the time of our having met, she was living with her two children, and I was living an appreciable distance away from her, and my employment required me to travel frequently, so we saw one another when I was around, but generally lived as a couple but distanced – as she had a young family, the arrangement worked for us.

12. In the latter part of my working life, when employed by a Swedish corporation near Chester, from which I operated as Managing Director responsible for their U.K. consumer products operations, we initiated another major expansion programme. However, then being 59 years old, and keeping in line with Swedish traditions, I was encouraged to move towards retirement and a replacement was sought for my role.

13. However, I continued in their employment to lead a special project on their behalf (to close a factory), following which, aged sixty I retired but just three weeks later I was advised (by them) to form a consultancy, and having done so I was recruited to work for them as a consultant, operating in the Philippines for two years and in Germany for three.

14. Joyce and I decided to set up home together, and went about building our own home in the grounds of the house in which I was then living. This was in 2003 , but the house took some five years to complete due to wrangling with planning issues, neighbours who objected and the like. Having built the house, Joyce and I moved in as a couple and married in 2008 on a cruise ship.

15. In so far as my health is concerned, there is no history of any blood borne ailments and I have not exposed myself to any of the known Hepatitis C risk factors, such as self-inflicted tattoos, intravenous drug abuse of promiscuous sexual activity. Like Joyce, I come from a family with a history of good health, and apart from an age-related hip replacement and a brief episode of high-blood pressure, consider myself to be very fit for my age.

Section 2 - How Infected

16. In 1986, Joyce had been going through the menopause. We were holidaying abroad when she collapsed and I had to bring her home, finding it necessary to use a wheelchair as she was so weak and lethargic.

17. On a separate occasion, whilst I was away working, Joyce experienced a very severe bleed. She laid on a couch, but found herself too weak to be able to get up again, she simply didn't have the strength to do so. She was bleeding, tired, weak and tearful.

18. Her General Practitioner (GP), Doctor Bob Jones attended and upon examination advised that she go to the H.M. Stanley Hospital in St. Asaph, immediately. She wasn't taken by ambulance, but travelled there by taxi.

19. The H.M. Stanley Hospital has since closed I believe in about 2010 or possibly earlier. It was located in Denbighshire.

20. The doctors at the hospital were astounded that Joyce had managed to get to the hospital under her own steam as she was found to be so weak upon arrival. She had suffered a major bleed, and was admitted. Joyce then spent two nights in the hospital, in a side room off of one of the wards, where she was given a blood transfusion.

21. I cannot now recall how the blood was administered myself, but Joyce remembers her having been connected to a bag of blood, quite possibly more than one, which was / were hung on a stand by her side. We don't know how much she was given, but her blood pressure upon admission had apparently been very low.

22. Joyce cannot now recall ever having given her consent for blood to be given to her, but she was extremely weak at the time and would have

been only too grateful for anything they may have been able to do to help her. I wasn't asked to provide consent, but at the time we weren't married, lived apart and 'partners' weren't treated in the same manner then as they may be today.

23. I say that we cannot state how much blood she was given as neither of us really know, we didn't ask at the time, and with the passage of time cannot now remember. However, she had to have been given at least one bag of blood on the day of her admission, as by the time I had been contacted and travelled to St Asaph, she had already received one unit and she stayed overnight being on another when I left, so there were at least two if not more delivered to her in between.

24. The clinicians engaged us in some discussion around the possibility of her requiring a hysterectomy, but it never materialised and after two or three days she was discharged home. Following her treatment, Joyce was then very much back to her normal self and felt completely rejuvenated.

25. Neither Joyce or I had been told anything of the blood she had been given, either before its administration had commenced (to Joyce, not that she may have remembered if it had been), during its administration or afterwards.

26. Having been a UK Blood Donor volunteer myself, for many years, I simply assumed that it had come from donors like myself, here in the U.K. Neither of us knew anything about HM Gov't. having been buying in whole blood or blood plasma from overseas and less reputable sources.

27. Neither of us had any cause for concern at the time, we trusted our doctors, believed they knew what was in our best interests and weren't in the habit of questioning their actions – and despite what has happened with Joyce, being of a certain age, I'd suggest that we come from a

generation who still feel this way and hold our medical professionals in the highest regard.

28. After several weeks, Joyce was contacted by the Consultant Obstetrician / Gynaecologist under whose care she had been given the transfusion, a Mr J.A. Edwards. She attended an outpatient's clinic where no tests were conducted, she was just told that she wouldn't need a hysterectomy as had at one point been thought likely.

29. At some time thereafter, and neither of us can now recall exactly when, whilst seeing her GP, we saw a letter which Mr Edwards had sent to Dr Jones which outlined the consultation mentioned above and her treatment, but made no mention whatsoever of the fact that she had been given blood.

30. With the exception of the one incident of heavy bleeding, and the query as to Joyce requiring a hysterectomy, she had experienced none of the typical menopause symptoms and her general health had remained good.

31. In the late eighties, Joyce read a newspaper article concerning contaminated blood having been imported from the USA, and panicked. All the same, at the time living in a small place like Rhyl, she concluded that 'things like that don't happen here,' and was able to push it to the back of her mind, especially as post-transfusion she had felt so well.

32. However, as time progressed and by the time we had moved in together in the new home, and as a result registered with a new G.P. in what for Joyce was a new area, she experienced bouts of inexplicably becoming tired, listless, and at times incredibly weak with these symptoms often coinciding with one another with more than one happening at the same time.

33. Joyce told me that she felt as she had when going through the menopause, but it was worse, far worse and she stayed like this until I managed to persuade her to go to the doctors – I physically had to take her as she simply didn't have the individual drive or physical ability to go of her own accord.

34. We saw a young GP, Doctor Swaro, who referred Joyce to our local hospital for blood tests. We didn't think too much about this as at the time we merely assumed that this was fairly standard practice for a new patient attending a fresh practice to see her new GP for the first time.

35. I took her to the hospital, but she was so weak that I had to put her into a wheelchair to be able to move her from place to place around the hospital corridors. She gave blood, but we were given no information as to what it would be tested for, either by the GP or at the hospital, so we didn't think anything was necessarily untoward, with the GP having said that the hospital would do the tests and that we'd hear from them in due course.

36. About ten days after her blood was taken, and by which time Joyce had been contacted by the hospital and given an outpatients appointment, we met with a hospital consultant who was accompanied by a specialist nurse, Angie Thompson. By some strange quirk of fate, Angie had been at school with one of Joyce's children, and she was to care for Joyce from that point onwards.

37. More blood was taken, and a general examination ensued, but nothing more, it all appeared as no more than a follow up from the initial referral of her G.P. However, within just a few days we received a 'phone call from Angie and Joyce was asked to go back in to see her.

38. Joyce's condition hadn't improved, we were still reliant on using a wheelchair to get her around, but she wasn't unduly concerned heading

into this meeting – and I always took the view that if something was wrong, then we'd find out what it was and resolve it.

39. We met with the same consultant and Angie Thompson who we found out to be a Senior Specialist Nurse Practitioner working across several health regions in Wales. It was during this consultation that we were told that Joyce had Hepatitis C. Thereafter, Joyce had to attend hospital at frequent intervals,, and whereas she saw the consultant every now and then, she saw Angie every time.

40. The HcV diagnosis came completely out of the blue and left Joyce extremely upset and tearful, but she was a little reassured as she believed herself to be in good hands – one of the patients attending the outpatient's clinic, on seeing Angie consoling Joyce following the diagnosis, asked if the nurse was a relative as she had appeared so compassionate towards her.

41. Having delivered the Hep' C diagnosis, the consultant remarked, with some amazement, that our GP (Dr Swaro) had done extremely well to have found something like this to have been the likely problem Joyce faced, which the majority missed. Perhaps this was as a result of Dr Swaro having been a young doctor at the time, and consequently a little more up-to-date than others, at least that is our opinion.

42. Like myself, Joyce had never exposed herself to the known risk factors associated with this ailment, she had no self-inflicted tattoos, had never used intravenous drugs, and had not been sexually promiscuous. The diagnosis was completely out of character for her, especially shocking as all we really knew at the time was that it was an illness related to drug abuse.

43. Both Joyce and I new little or nothing of Hepatitis C when it was diagnosed, and in our ignorance thought that it was some 'strand' of HIV, something which we thought only affected certain individuals with a

particular lifestyle – we knew nothing. Unfortunately, the nature of the illness was not explained to us, which may have helped, but at the time the news was rather overwhelming.

44. Although we were told that Joyce had Hep' C, we weren't told what Hep' C was, how she may have come by it, and perhaps just as importantly, what damage it would do to Joyce if it remained untreated and the extent of any damage she may have already sustained, we were left to find out for ourselves.

45. Having been rather shocked and taken aback by the diagnosis, especially when considering what we errantly understood of Hepatitis C, neither Joyce or I asked for any further information or explored how she had contracted the disease at that time. Post-diagnosis, I started looking for information. Initially I found an old Readers Digest health publication which helped, but didn't mention any possible treatments, so we learned a little of what HcV did, but not what could be done about it.

46. Internet searching was a little more useful, and we found out various means of transmission including, importantly in Joyce's case, that it could be passed on through blood transfusion – I found out about blood having been taken from drug addicts and other infected persons overseas, which had found its way into the blood supply. Again the information I gained from internet searching helped, but was heavily weighted around those who had contracted HIV with very little about Hepatitis C.

47. Joyce's blood transfusion had been over twenty years before, and despite what we had learned, our knowledge was far from complete, and left more questions than answers – how could she have caught Hep' C from a blood transfusion only for it not to present itself for over twenty years? Concerned that excessive research would only lead to more worry, and little or no cause for optimism, I stopped researching Hepatitis C as I felt that it was causing us more harm than good.

48. Joyce and I had learned that HcV could damage the liver, but when first diagnosed with Hep' C, she wasn't told of the condition her liver may have been in or the effect the disease would have upon it, nor were we given any guidance as to 'best practise' as regards her being able to look after her liver whilst living with Hepatitis C. Fortunately, Joyce had never consumed any form of alcohol and never would, being tea-total, and has never smoked, which must have helped and would help as she moved on with the disease.

49. We were not provided with any information as to how we may prevent the virus being passed from Joyce to myself, or others including no precautionary measures we may have needed to adopt as regards sexual contact.

50. We were advised that I needed to submit to an HcV test, and that it would be advisable for other close family members to be screened for the disease as well. We all submitted to tests and fortunately all were returned negative, but it was a worrying time for all, especially Joyce who feared she may have infected others, albeit unknowingly.

51. During the course of a further consultation, her consultant asked if she had ever received a blood transfusion – she told him of the 'heavy bleeds' and of the blood transfusion she had been given as a result, and he stated that this had been the source of the Hepatitis C. There was absolutely no doubt in his mind, although we were left a little confused as he didn't explain how the blood used may have become contaminated and because we thought that the NHS only used blood obtained from voluntary donors like me, here in the UK.

52. Treatment options were also discussed, and the consultant outlined his intention to treat Joyce with a combination of the drugs Interferon and Ribavirin. We were told that the proposed course of treatment would last for several months and that throughout and thereafter, she would be

monitored to ascertain the effectiveness of the treatment and its impact, if any, upon her Hepatitis C viral load, hoping to see a reduction. It was explained to us that her viral load was then measurable in several thousands (of what, I do not know), and the objective was to reduce it to zero.

53. I can't now recall if it was the consultant or Angie who told us, but we were told that the medication she was to take had been found to be very difficult to tolerate and that not all patients treated with this combination of drugs were able to complete the course. We weren't told how Joyce may react, or what side effects she may experience, just that it could be quite tough. We weren't told of the chances of it being successful, or given any other options for treatment – at that time, this appeared to be the only one.

54. Joyce was told how the drugs were to be taken and she was given an injection kit and shown how to use it, as she would have to self-administer one of the drugs by injecting it into her abdomen. Angie Thompson showed her how to do this.

Section 3 - Other Infections

55. In so far as Joyce or I am aware, her blood has never been tested for HIV. This doesn't mean to say that it hasn't been, just that we are unaware of that having taken place. In any event she has not been diagnosed with HIV or any other disease which she may have contracted as a result of the contaminated blood she had been given.

56. With the benefit of hindsight, if Joyce or I were tested for HIV, I am rather glad that we weren't told and it may have been wise for us not to have been, it would, quite frankly, have frightened the life out of us to know that there was any likelihood of us having HIV – it had been

widely reported upon, was a dreadful ailment, and we had been led to believe that if you caught it, you would die.

Section 4 - Consent

57. I have already spoken on the subject of 'consent' as regards the blood transfusion she had been given and our approach to the medical profession in general having been that of 'Doctor knows best.' Equally I have mentioned, above, our thoughts as regards any HIV testing that may have taken place without our knowledge or consent.

58. Told that it could be unpleasant, and that not everyone was treated successfully, Joyce nevertheless gave consent for treatment with a course of Interferon and Ribavirin, but given the situation which arose whilst she was taking it, as later detailed, I am not sure if this would necessarily have been the case had she known just how bad it was going to be.

Section 5 - Impact

59. The impact of having Hepatitis C, the treatment for it, and its legacy has had a major impact upon Joyce, her health and wellbeing, and by consequence those around her. Her illnesses, all unexplained and which appeared almost continual leading into the eventual diagnosis had taken their toll on her physically and mentally as she found herself unable to do things, even the most simple of tasks left her exhausted, and she worried as to what was going on, what was happening to her.

60. Joyce commenced treatment with the drug combination in 2013, some twenty seven years after the blood transfusion which caused her to have become infected with Hepatitis C. By the time the disease manifested itself, it had already been taking its toll as not only did she present with the symptoms previously mentioned, but had been prone to catching any 'bug' that may have been going around for some time beforehand.

61. Having commenced treatment, Joyce had to return every fortnight to the Glan Clwyd Hospital in Rhyl, Denbighshire for her progress to be monitored. On one visit, she had to undergo a liver biopsy – this was a painful procedure which left her uncomfortable for a while, but which was undertaken as a day case, with my having collected her and taken her home the same evening.

62. When returning two weeks later, Joyce was told that she had mild liver disease, but that her HcV viral load was diminishing as she progressed with the treatment. Joyce was given the liver disease diagnosis by the consultant, but it wasn't stressed as having been anything particularly serious, but that it would nevertheless be monitored. She was given no more information than that.

63. During the course of her treatment, Joyce's health noticeably deteriorated. She had already been debilitated by the disease but her condition had worsened to a point where she found herself unable to move around the house, so she had to sleep on a couch as she couldn't manage the stairs.

64. At this time, I had retired but was heavily involved in voluntary work, so the burden of her care fell upon myself and her children who had to look after her – everyday tasks, simple things such as going to the toilet or even using a comb had become impossible and she could do nothing for herself being wholly reliant upon her family and I.

65. Joyce found it difficult to eat, and was often found asleep or extremely lethargic, at a really low ebb both physically and mentally. Her GP, in an effort to help, prescribed high calorie yoghurt, but she couldn't even eat that. It was a very worrying time for us all, as despite the fact that she was on treatment and meant to be getting better, she actually appeared to be getting a lot worse.

66. Joyce was being told by the clinicians that her viral load was decreasing, and we were assured that the treatment was being successful, but in spite of what we were being told, she was clearly growing increasingly unwell. I was so concerned that I contacted her GP and took her to an appointment with Dr Swaro.

67. The GP could see how poorly she appeared, and promised that he'd speak to her consultant, as he, like us, was concerned that her health deterioration had been so rapid that if she didn't stop taking the HcV treatment she may not survive it.

68. The GP contacted the hospital consultant and when we returned for her next monitoring appointment, Joyce and I met with her consultant who stated that Dr Swaro had suggested that her treatment cease. However, the consultant disagreed with this consideration and asked Joyce for her view on things, but she was quite ambivalent, perhaps a reflection of just how low she felt at that time.

69. The consultant recommended Joyce pursue the treatment plan for a further two to three months, as the viral load was decreasing and her achieving a zero reading was thought viable, although it could not be guaranteed and the GP and I were concerned that she may not be able to continue for much longer.

70. She carried on, but the health situation remained and I made the decision for her, that she should cease treatment. We met with the consultant again, and I impressed upon him just how poorly she was, how unable to care for herself she had become, and how her decline had continued. I told him that she simply would not be able to see the course through. He again asked Joyce for her opinion, and she agreed with me, she had had enough.

71. So, after some three to four months of her taking Interferon and Ribavirin, and with a decreasing viral load but deteriorating health, Joyce stopped taking this treatment, but from what I recall of the conversations of that time, the consultant considered that the effect of the drugs taken could continue, but no one knew how well or for how long and with what impact.

72. Although Joyce continued to have six monthly review appointments, we never saw the consultant again, just Angie Thompson. She supported our decision to stop, understood our reasons, and was very sympathetic, especially with regard to the severity of the side effects she had experienced. Blood tests were taken when they met, but mostly they simply engaged in a conversation as to her general health and welfare.

73. Having come off of the treatment regime, Joyce's health gradually improved, slowly but noticeable as time progressed – there wasn't the same sort of speedy recovery she had experienced immediately following the 1986 blood transfusion, but slow and steady advancement. After some months she felt considerably better and was recovering in the absence of any other tonics or alternative medication.

74. In 2015, during the course of a six monthly review with Angie Thompson, it was suggested that Joyce could possibly be given a different course of Hepatitis C treatment with a drug called Harvoni, a drug which apparently came with no adverse side effects.

75. Angie explained that Harvoni wasn't generally available on the National Health Service, as it was only being trialled, and there was no guarantee that Joyce would be accepted as a clinical trialist, but she advised Joyce that as she had been unsuccessful using Interferon and Ribavirin, she would be considered a good candidate for using Harvoni so Joyce told her that she was
'interested.'

76. On her next visit to see Angie Thompson, Joyce was told that she had been accepted onto the trial and could begin a course of HcV treatment using Harvoni which would necessitate her taking a tablet daily, over fifty six days. Joyce's health was by now stable and she felt well with no symptoms. She was delighted to have been accepted onto the trial which offered real hope, a better means of administration, and no ill effects.

77. Joyce commenced treatment, and was monitored over a two-year period. She was initially given a twenty-eight day course of tablets, then had too return to see Angie for monitoring and too be given a further supply to take her to the course end. Upon completion, she returned to see the nurse specialist and provided blood for testing, a situation which continued every three to four months over two years. Her viral load decreased, and by May 2017 was measured at having been less than twelve.

78. In September, 2017 over thirty years since she had become infected with Hepatitis C, Joyce was told that her HcV had been eradicated, albeit that antibodies would remain. She was at last clear of the disease and in advance of meeting with the Infected Blood Inquiry in order to provide this statement I looked at old diaries and found an entry from this time where I had written, "Joyce, the lucky one."

79. Further good news came when she was told that she no longer needed to have her liver monitored, and she was discharged. She hasn't had to return to the hospital since and has apparently improved to the extent that she doesn't require any additional monitoring through her GP either.

80. Joyce had to attend a lot of hospital appointments from the point of her initial diagnosis of having Hepatitis C until her final discharge. For each appointment her medical file would be present in the room and within our view. We remember seeing that a yellow sticker had been placed

on her file and other notes which showed her as being infected and presenting a health hazard to others.

81. Joyce found this very embarrassing and was conscious of it, singling her out from other patients as someone to be wary of, which she disliked a lot. It was difficult for her to deal with and played on her mind.

82. She worried that her friends may not believe the source of her infection and we took a conscious decision to only tell immediate family and close friends, it never went any further and was considered to be a taboo subject as we were worried what others would think and the judgements they may make about us.

83. Joyce found telling her children that she had Hepatitis C a very difficult thing to have had to do. Her eldest child had worked in nursing throughout her adult life and eventually became a full-time carer specialising in care of the elderly. She was better placed than others, and appeared to take the news of her mother's diagnosis in her stride, particularly as she had experience of patients with HcV, but it didn't make it any easier for Joyce to deal with.

84. Her youngest was also very accepting, which was a great relief to Joyce, but she had to suggest that both get tested for Hep' C which she found a terribly hard thing to have to do, and which then caused us all some anxiety. As a mother she feared she had passed something on to her children, and feared for the consequences until the results were received.

85. She was not only embarrassed to have been told that she had Hep' C, but it made her feel dirty as we both associated the condition with drug-taking. We both worried about the stigma attached to hepatitis, which had been so closely linked in the media to HIV and AIDS, and she

found it very difficult to confide in others which made things socially difficult at times.

86. Joyce found that she had to divulge her Hepatitis C status to her dental practise which she again found a great embarrassment but something which she would had to do as it would have been unfair and irresponsible of her not to have done. Fortunately, her dentist appreciated her candour and took steps to reassure her didn't treat her any differently to other patients.

87. I found things very difficult, especially if I was away from home and had to leave her in the hands of her children. It was also very hard to deal with as there was absolutely nothing that I could do to help other than offer my support. No support was offered from other sources, the GP or hospital for example, by way of counselling or psychological support, so I tried to fill the gap as best as I could, but it was a very difficult time for us all.

Section 6 - Treatment / Care / Support

88. Having said that we were at no time offered any form of counselling or psychological support, looking back neither of us can see that it would have been of much help as we were so fixed on her clearing this virus. Once Joyce found out that the Harvoni was working, she was elated.

89. When Joyce was diagnosed as having Hepatitis C, we both felt extremely lucky that Dr Swaro had been astute enough to have referred her to a consultant when he first suspected a blood borne disease to be at the core of her health issues. Even the consultant doubted if he would have thought the same as her GP when presented with a lady of her age and the same symptoms – it makes me wonder how many other ladies may have had HcV which passed as 'menopausal conditions' rather than for what it actually was.

Section 7 - Financial Assistance

90. In around January 2013, one or possibly two meetings with the consultant following his initial diagnosis of Hep' C, we were asked if we knew of The Skipton Fund? He explained to us that a scheme had been established to assist people who had become infected as a result of their having been given contaminated blood and / or contaminated blood products.

91. The consultant suggested that Joyce could be entitled to a financial payment of anything up to £20,000- and gave us the address to contact with a promise to support any claim she may make. Angie had also been present at this conversation, but had not mentioned it to us before. Until then, neither Joyce or I had any knowledge of The Skipton Fund.

92. Joyce and I decided to apply. We obtained the relevant forms, gathered our facts together, as best as we knew them from so many years before, and sent them off. Joyce was already planning what to do with the money which she wanted to divide between her children, as it helped address her feeling of guilt at the fact that she may have infected them and had caused them to have to be tested, it would have been some sort of compensation for that.

93. The Skipton Fund requested sight of relevant medical records to support her claim. We managed to secure some paperwork from her initial GP, Dr Bob Jones, but he had been an old-fashioned doctor who didn't write much down and what he did was in note form with the legibility of his notes proving difficult to decipher.

94. Joyce had been transfused at the H.M. Stanley Hospital, but that had since closed with records having been transferred to the Glan Clwyd Hospital where she had been diagnosed as having HcV. Unfortunately, they could find no notes regarding Joyce from the HM Stanley Hospital.

95. The Skipton Fund declined her application as a result of the lack of supportive medical records we were able to produce, notwithstanding the fact that we hadn't actually misplaced them and the events to which they would have referred had been many years before.

96. Joyce appealed against the decision and I spoke to them by 'phone on her behalf as I had helped complete the forms and was familiar with their content. A clerk with whom I spoke was very pleasant and suggested that I reapply to the hospital, so I wrote to the Betsi Cadwaladr University Health Board (who manage the Glan Clwyd Hospital), but received a very curt response to the effect that her records 'were not available.'

97. Joyce and I appealed on two further occasions, but a lack of hospital records always appeared to be the stumbling block. The health board repeatedly informed us that her records weren't available and The Skipton Fund repeatedly told us that their remit prevented them from proceeding with applications in the absence of medical records.

98. The Skipton Fund simply wouldn't accept our argument that she had been given HcV by the NHS, via a blood transfusion as there was no other means through which she could have come by such a disease, a position supported by the consultant treating the disease and a specialist in that field. It was very frustrating and seemed all too convenient that NHS records which could have supported her application had gone missing.

99. After some time, the health board stated that they were undertaking investigations regarding 'missing records.' Nothing came of this so I asked again and was finally told that all patient records for the period 1985 until 1990 had been destroyed.

100. I was frustrated, annoyed and disappointed as Joyce's application to the fund was rejected on three occasions and all a result of her records having been destroyed. I challenged the board on grounds of

mismanagement, arguing that the records should not have been destroyed but at the very least archived – Joyce was still alive and being treated under the same board, so how had they been disposed of without even seeking her authority first? Had their action been lawful? Should they not have been placed in the National Archive?

101. My complaint was declined, rejected by the hospital board who claimed their actions to have been lawful. I wrote to the Information Commissioner's Office (Wales) again claiming maladministration but they too rejected my complaint with a suggestion that if we wanted to take matters further, we would have to take it as a private matter through the civil court.

102. Joyce and I then took the decision not to pursue things any further, and that she was no longer 'Lucky Joyce' but a victim of 'the system,' but I wouldn't let it go. In around 2015, I consulted the Public Services Ombudsman (Wales) who, apologising for being unable to help us, expressed a willingness to assist and asked if we were aware of the Wales Infected Blood Support Scheme (or 'WIBSS').

103. Having told him that we were unaware of WIBSS, he encouraged us to contact them as they had apparently taken over from The Skipton Fund. Joyce and I had also been talking to our local Member of Parliament, David Hanson MP who contacted us to inform us of a meeting being held in Bangor by the Infected Blood Inquiry – he emailed us details of the location, date time etc. and explained that we needed to register with the Inquiry in order to attend, which we duly did.

104. Mr Hanson had also been in contact with the Betsi Cadwaladr University Health Board on our behalf and had asked them for further information. He had even mentioned our circumstances in parliament. He subsequently told us that the actions of the hospital board in destroying Joyce's records, although ethically contentious, had not been illegal.

105. On 17th February 2020, Joyce and I attended the Infected Blood Inquiry meeting held in Bangor. We weren't at all sure about attending, and even when we got there we stood in the car park, half way between the car and the entry door, debating whether or not to go in, but we did. There were about fifteen other members of the public present and three administrators.

106. A lady introduced herself and provided an oversight of the Inquiry and process of previous meetings held elsewhere then opened the meeting to the floor. It then became apparent that many of those in attendance were in receipt of benefits and / or other financial assistance of one form or another. Until then, Joyce and I had been unaware of the various sources of assistance which had existed and were surprised by the difference in the levels of financial assistance which could be achieved – we were quite clueless in this regard.

107. We were invited to introduce ourselves to the group, which we did, providing a potted history of Joyce's situation and the repeated rejections she had experienced with The Skipton Fund. We were asked 'why' our application had been declined and explained how the lack of medical records had impacted upon us.

108. The lady chair of the meeting directed us to the WIBSS and promised to send us an application form, which she did. We completed them, as we had those for Skipton beforehand, and having paid a £25-fee to Joyce's GP for completion of a section in support of the claim, sent it off.

109. Joyce and I heard nothing for months, and were beginning to feel that it had again been unsuccessful but then a lady from WIBSS called and explained that she had 'good news' for us. The application had been accepted and approved – we should receive a letter within a few days, and Joyce had been awarded the sum of £20,000-.

110. We subsequently received a further payment of £5,000-, some form of backdated payment as by this time her application had been almost twelve months old, so she received £25,000-. In around late July / Early August, 2021 we received a further letter from WIBSS, telling us that in order for WIBSS to fall in line with arrangements in England and Scotland, she would be receiving yet another lump sum payment, and she began receiving a monthly fee of approximately £400. Subsequently, a further lump sum and a revised monthly fee were granted to Joyce in line with the arrangements to be found in England and Scotland.

Section 8 - Other

111. I cannot help but feel that there was absolutely no reason why The Skipton Fund could not have approved Joyce's initial application, and as a result she could have been in receipt of financial assistance, if not adequate compensation for all that she has experienced, at least ten years before she actually did, so she has unfairly lost what could have been very useful income at a most challenging time.

112. It seemed to us that rather than their having been established to help people like Joyce, who through no fault of their own had become victims of the contaminated blood scandal, the Skipton Fund sought to use whatever means at their disposal to decline payments.

113. The application process turned into a real battle, which was unnecessary and caused both Joyce and I a great deal of stress and anxiety. We were unnecessarily challenged to prove something which was impossible to do as the NHS had disposed of the evidence, yet we were somehow held responsible for that.

114. WIBBS, by contrast, although having initially been a little slow, have been communicative, courteous, helpful and understanding. It is just

a shame that when Joyce was first diagnosed, The Skipton Fund had no information available "at source' in the hospital and that we only found out about WIBSS following our having engaged our local MP and then having attended the Inquiry meeting.

115. Joyce is now much better, but legacy issues mean that she still has memory lapses and suffers from fatigue at times, hence my having made this statement on her behalf – I also dealt with all of the applications, appeals and other initiatives we undertook with and concerning the Skipton Fund and then with WIBSS and others.

Statement of Truth

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

Signed: GRO-C

Dated: GRO-C 06/01/2022