Witness Name: Pamela Dwyer
Statement No.: WITN2696001
Exhibits: 0
Dated: 11 October 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAMELA DWYER

Section 1. Introduction

1. I, Pamela Dwyer, will say as follows: -

2. My date of birth is GRO-C 1959. My address is known to the Inquiry.

3. My husband, Gary Dwyer, has already submitted a statement to the Inquiry and I make this statement to support his statement and to add any facts to the history.

Section 2. How Affected

4. I met my husband, Gary Dwyer, in 1978 and we married on 14th June 1980. In 1972, at the age of 14, Gary had developed Lederer's haemolytic anaemia and, due to this condition, he was admitted to Warrington General Hospital, where he was given a transfusion of whole

blood to treat the acute anaemia. It would be many years before Gary became aware that the blood used for his transfusion in 1972 was contaminated with Hepatitis C (HCV).

5. When Gary and I first met in 1978 he was 20 years old and appeared to be a normal, active young man with a full healthy life in front of him. We began married life like any young couple, expecting that with hard work and perseverance we would achieve our aspirations and have a family together. Gary suffered from lethargy, psoriasis and felt generally unwell, often with flu like symptoms. His GP treated his skin problems and prescribed iron tablets but never suggested blood tests to check on his previous condition.

6. Gradually Gary's health problems worsened which meant he had to take more sick leave than the average person and was frequently made redundant, finding it difficult to obtain another job. I believe this was very stressful for Gary.

7. In 1988 I became pregnant with our son. He was born prematurely on GRO-C.1988 at Whiston Hospital. I was questioned many times about my lifestyle, especially smoking and alcohol consumption, because our son was not only born early, he was regarded as underweight for his gestational weeks (birth weight 3lbs 12ozs). I have never smoked and did not drink any alcohol during my pregnancy but to my knowledge no tests were carried out to investigate this issue further even though my placenta had failed. The average placenta weighs 4lbs, my placenta weighed 12ozs.

8. Gary worked night shifts and overtime to help finance my maternity leave, however his health deteriorated further and I had to return to work much sooner than I had hoped. Gary was now suffering with stomach pain, nausea and bouts of diarrhoea. One day I noticed Gary appeared

jaundiced so I immediately made him an appointment to visit his GP yet again. I insisted, on this occasion, that he did not come home without the paperwork to go for blood tests as I believed he had an underlying problem that had never been properly diagnosed.

9. The GP ordered blood tests and the results showed abnormal liver function and so Gary was referred to the Whiston Hospital in February 1990. The consultant gastroenterologist diagnosed Gary with HCV.

10. The results of Gary's tests were not discussed with him in any detail and he was given very little information about the infection. The only advice he was given, and has ever been given, was by Mr Faizallah in 1990 when he strongly suggested that Gary gave up alcohol completely for the foreseeable future. If he did not, Gary told me that Mr Faizallah had warned him he would very likely develop liver cancer and die a premature death. Mr Faizallah also suggested, because we had holidayed in the former Yugoslavia the previous year that Gary could have contracted HCV from the dairy products. My parents and I had also consumed the same dairy products, so this idea seemed very unlikely. I think this information about dairy products was misleading and did not help us with identifying the true source of infection.

11. Gary and I cannot recall his GP giving him any information at all about his infection with HCV or how to manage it. Moreover, there was no mention at all from any medical professional that the infection might have been caused by his blood transfusion in 1972. Both of our GPs showed a total lack of sympathy for our situation.

12. Gary and I were not given adequate information to understand and manage the infection. I believe we should have been given much more information at the time he was diagnosed, including that it was likely to have been a blood transfusion which was the route of infection. My

husband was diagnosed in 1990 and I believe Hepatitis C had been acknowledged as a notifiable virus in 1988. Once Gary was diagnosed why was he not immediately informed that he was very likely to have been infected through contaminated blood and given as much information about the effects of the disease as was known at this time?

13. We were given no information at all about the risks of others being infected as a result of the infection. Later in 1990, when Mr Faizallah offered Gary treatment with Interferon B, I made an appointment with my GP at that time, Dr Barbara Bainbridge, to ask for help and advice. I asked her if Gary should go ahead with this treatment when it was likely to be as severe as chemotherapy and may not cure him anyway. She informed me that Gary should take the offer of the treatment, so long as Mr Faizallah was going to fund it and she said she had no budget for any treatment. Dr Bainbridge said that if Gary didn't have the Interferon B injections he would be likely to develop liver cancer. I asked, given he was so young and had a baby son, would he be eligible for a liver transplant? Her answer was to shrug her shoulders, saying there was very little chance of that. I also specifically asked her if either myself or my baby were at risk of contracting the virus from my husband. I don't remember her answering that question, as she was much more concerned with reiterating that her surgery could not fund any treatment for Gary. I remember feeling totally devastated by her attitude. I believe this was the trigger that started my personal battle with depression and anxiety. Without the support of a sympathetic GP I found it very difficult to cope.

Section 3. Other Infections

14. I do not believe that Gary received any infection other than HCV as a result of being given infected blood.

Section 4. Consent

15. I do not know whether Gary was treated or tested without his knowledge or consent or for the purposes of research.

Section 5. Impact

16. The impact of the infection on my husband is set out in his statement. As for me, I was very shocked and frightened. I tried to understand what the diagnosis meant in order to come to terms with it, but we didn't get answers to so many of our questions that I felt it was very difficult to digest. I found it very hard to handle because I didn't know what I was dealing with. Gary was so poorly that we just had to deal with each day as it came. I felt he was under a death sentence and it was more a question of when was he going to die than whether he would die. Life became very serious and we battened down the hatches in response and made our lives very small so that we could cope.

17. In 2017, as set out in his statement, Gary started to have a problem with his right hand and right shoulder. His GP noticed evidence of HCV in his medical records and informed him that trigger finger can be linked to liver function and recommended a blood test. This test revealed Gary was still positive for HCV. He was devastated as he knew the virus had continued to attack his body for decades and the Interferon treatment from 1990 had been unsuccessful but he had never been informed. I found this news worse than the initial diagnosis in 1990. If Gary had remained clear after the initial treatment with Interferon we might have come to terms with things: it had been very difficult but we had come through it and he was ok, but finding out that he remained positive for HCV left us with so many unknowns.

18. Gary underwent numerous investigations for his HCV infection, including blood tests, ultrasounds and a liver biopsy. The biopsy was a particularly difficult experience as it took three attempts and they caught Gary's rib with the needle. Gary went into shock and the nurse tipped his bed the wrong way and he fell part way out of a third flood hospital window. When I arrived I was questioned about his blood pressure and whether it was usually low. When I asked what it was before the biopsy they said they didn't know because they didn't take it. I was very surprised that they hadn't undertaken this basic monitoring of his blood pressure. Gary was very affected by the hospital admission and was desperate to come home: the bathroom he had to use was very dirty, with blood and faeces from other patients, so Gary was very worried he might catch something. He felt helpless and hopeless. I had to ask hospital staff for it to be cleaned up. Many of my experiences in hospital when I am trying to support Gary have resulted in arguments with staff. I have found these experiences very hard and have often come home very upset.

19. Gary began treatment with Interferon B in 1990 which was experimental at that time and his statement describes how he felt during and after treatment. For me, the worst part of his treatment came when he did not want to take the Interferon anymore because it made him so ill. I felt that I had to make him take it because I couldn't see any alternative to it: it was Interferon or liver cancer. I would be quite aggressive with him, telling him to take it, telling him he was not going to die on me and our son. He would stick the needle in and twenty minutes later would be shivering and shaking and would take himself to bed. I would sit and cry for a couple of hours because I felt so guilty. It was always on a Sunday, so that was our Sunday afternoon and evening for months and months.

20. In 2018, after finding out that his HCV had never in fact been cleared after treatment in 1990, Gary began treatment with Zepatier. This second round of treatment was slightly easier to bear because he wasn't

so dreadfully ill as he was with the Interferon. However, even though the Zepatier wasn't supposed to have many side effects, Gary had only been taking it for two weeks when he found he could no longer sleep at night. We didn't know whether this was a side effect of the drug or Gary's anxiety at the return of the HCV and fear that further treatment would not work. It became a lot more difficult for Gary to do his job because he was so tired and lethargic. I was very worried about him working during treatment: he drove 40ft lorries on busy motorways but he wasn't sleeping at night. I would worry all day until he came home. If he was late I would worry more, but I couldn't call him because I didn't want to distract him whilst he was driving. There was no other option for him: he couldn't afford not to work and, at 62 years old, couldn't suddenly find a desk job. It leaves me at a loss as to what he was supposed to do. He met with occupational health and took his medication with him, including the Zepatier. His employers agreed, due to the lethargy and lack of sleep, to limit his working day to nine hours of driving, which are his contractual hours. However, he would frequently be asked to work longer than nine hours when he turned up to work for his shift, and this frequently resulted in arguments. This affected his confidence at work and he began to feel very depressed about attending work each day. He seemed to be deteriorating physically too, as the pain in his hands and his joints was worsening. He was physically struggling with work so much that he had to take time off sick and remains on sick leave. I fear he will never go back to work because he is simply not getting any better.

21. Gary is still on sick leave from work and is becoming more and more depressed. He is now only eligible for statutory sick pay and if he didn't get the money from EIBSS I don't know what we would do. Since making his statement for the Inquiry last year he has deteriorated and yet we are being told that he cannot get any worse. It seems the Zepatier has cured the HCV but he is still suffering from the effects: we feel very stuck at the moment as we cannot see a way forward.

22. Gary has asked his GP for counselling and was put on a waiting list three months ago, which he is still on. When he asked for the referral he was told he was not a priority because he had me to support him and he was not suicidal. I feel he should have been offered counselling by now. Our GP, Dr Brown, sympathises but says this element is of the NHS is very underfunded so she cannot offer counselling any sooner.

23. We have changed GPs to a new GP and she is very helpful, but I try to always accompany Gary to his appointments because he is now very forgetful: if I cannot go with him we have to make a list otherwise he forgets what he needs to tell the GP. Since he has had the Zepatier he thinks his memory has got worse. We thought there were very few side effects to Zepatier, but having gone through the treatment Gary believes it stops him sleeping, raises anxiety, and may cause depression. Even though he has now stopped taking Zepatier his brain remains foggy and he still does not sleep well. He takes anti-depressants and extra pain killers.

24. As set out above, Gary was diagnosed in 1990 and treated with Interferon. He was then once again found to be positive for HCV in 2018 and treated with Zepatier. The experience of Gary being rediagnosed with HCV all these years later has reinforced for me the vital importance of follow-up. When he received treatment with Interferon in 1990 we were told there was a less than 50% chance of clearing the virus. If this statistic was known, why were people left with no follow-up when there was a good chance they would not clear the virus? When Gary was diagnosed with HCV in 2018 the nurse said she couldn't understand how he was still alive as many people would have developed liver cancer in that time. She said that all this could have been avoided if there had just been some follow-up after his initial treatment with Interferon. I don't know when Zepatier first became available for treatment but I wonder

whether Gary could have been treated earlier than 2018, thereby avoiding some of the years when he continued to have the virus in his system.

25. Gary's statement sets out the effect HCV has had on his social, family and private life. Socially, we had to decline all invitations to any events where alcohol might be served as Gary did not want to explain why he could not drink as there was a lot of stigma around HCV at that time. When you do not socialise you lose your friends, because they keep asking and you never come, so they stop asking. We even lost contact with family members. Although we tried to explain our situation, we found that friends and family didn't understand: because Gary was still working people thought there was nothing wrong. I found explaining things humiliating and exhausting: friends would still say, 'yeah, he can have a drink though, can't he?' and you have to keep repeatedly refusing them. People wanted the old Pam and Gary back, the life and soul of the party, and I think they thought us odd. I found it easier not to socialise: I had had enough of explaining myself, only to be dismissed. I found people didn't listen to what I was actually saying, and I started to avoid friends and acquaintances because the lack of understanding and sympathy was hurtful and frustrating.

26. As for family life, as set out in his statement, Gary was unable to play with our son very much when he was young. I myself had very little time to give our son the attention he deserved because I had a full time, demanding job and a sick husband. Between work, hospital visits and household chores my days were very full. Our son was fragile and I wished I had been able to spend more time with him during his childhood. When our son was around three years old I was transferred from my company's local office to a site 15 miles away. The extra 30 miles round trip added another hour to an hour and a half of travel time each day which meant I had even less quality time with my young son. I still feel

guilty and upset to think how much my baby missed out on fun times with his parents. No matter what else needed to be done I always used bath-time as play time and bed time stories were sacrosanct. I like to think this led to my son's love of literature and his choice to become an English Language/Creative Writing teacher following his Masters degree.

27. As for our private life, Gary's statement describes how his condition has affected nearly every day of our 39 years of marriage. He felt we should not have any more children once he was diagnosed as he would probably not live long enough to support our family, let alone another baby. I agreed not to have another baby but became very sad when Gary had a vasectomy at the age of 36. I hated that our son would never have a sibling. Gary is an only child and told me how he had always wished for a brother or sister. I was broken hearted that our son would now always be an only child. I became very unhappy and depressed following the vasectomy, which led to us separating for a short time. We have since got back together and try to make the most of our circumstances.

28. I have suffered with anxiety and depression ever since Gary was fist diagnosed with HCV. The lack of support from the various GPs I saw at my local practice over the years has left me feeling very isolated. I tried to ask for help from my GP on many occasions but I think I was just dismissed as an attention seeker. No GP ever questioned me enough to get to the root of the problem, and there was never any mention of counselling of any sort. I felt they viewed me as something of a hypochondriac when I asked for help with neck pain, migraines, fatigue, lack of sleep and anxiety.

29. Eventually, I decided I needed to find help outside of the NHS, so I arranged a consultation with the St. Helens Chiropractic and Acupuncture Clinic. The practitioner who assessed me discovered that my neck pain

was due to the muscles in my higher back being in spasm, a common problem usually caused by hunching of the shoulders in a self-protective reaction to the severe headaches/migraines I had been suffering for a long period of time. I needed several acupuncture treatments to make the muscles relax sufficiently for the practitioner to massage my back to encourage the muscles to relax further. Although the treatment was expensive, we decided it was worth economising on other things, because if my health improved I was better able to cope with our problems. I had regular treatments for several years, despite the cost being substantial for us, until my practitioner stopped practising. I tried to find another acupuncturist but was never as comfortable as I had been with my former practitioner so the treatments were not as effective. I therefore gave up the treatments because of this and the high costs of private treatment. The migraines returned and have continued to some extent ever since. This treatment got me through many years of coping with my job, which was very busy but which I had to keep in order to pay the mortgage. About the same time my practitioner retired my employer was making many redundancies, so I decided to take early retirement because I felt I could no longer cope at work. By this time we had managed to pay off our mortgage, which was another reason I felt I could retire.

30. I have never been offered acupuncture or any alternative treatment by my GP practice for my health problems nor have I ever been referred for counselling even though one of the GPs at my surgery prescribed an anti-depressant, fluoxetine, around 15 years ago. I have been taking this medication ever since. I was considering giving up the anti-depressants when Gary began having HCV symptoms again and the shock of his blood test result in 2018 showing Gary was still infected with HCV resulted in my anxiety becoming worse than ever. I remain on anti-depressants and these help level my mood. I believe I have felt so anxious now for so many years, waiting for the axe to fall, that it has

changed me as a person. I used to be a happy go lucky sort of person, but not any more.

31. In terms of stigma, Gary had told his previous employers about his infection but they nevertheless began disciplinary proceedings. After this experience we realised we needed to limit the damage that had been made to Gary's self-esteem as far as possible in the future. HCV became our 'nasty' secret as Gary felt unable to tell anyone apart from me. The infection was only discussed between us and otherwise only on a 'need to know' basis, for example with medical professionals. This protected us from further prejudice but was a great burden to us both and we felt very isolated.

32. With wider family, we did not discuss Gary's condition, which sometimes led to disagreements over family celebrations. We became the odd, tea-totalling couple. It is only since Gary's second HCV positive diagnosis in 2018 that we have told our son about his father's infection and been more open about it with other members of our family. Keeping this secret has been very stressful and I believe caused difficulties in the relationship I have with my two brothers. I no longer have contact with my younger brother. Our son was very shocked when he was told of his father's condition but understands that for many years he was far too young to be worrying all the time about his father's health.

33. With medical professionals, both Gary and I felt both he and his infection were treated with suspicion, fear and sometimes contempt. This was both of our experiences up until he encountered the special care nurse at Warrington General Hospital in 2018. This nurse, Pauline Kua, has always provided fantastic care, and been kind and considerate towards Gary. It was Pauline who explained to him about the financial assistance available.

34. More recently, since Gary submitted his statement to the Inquiry last year, we have been very upset by the way he has been treated by his doctor. At his most recent appointment at Warrington Hospital on 16 July 2019, he met with Dr Bhati and his specialist nurse, Pauline Kua. Gary attended alone as I could not go with him at the time. When he came home, Gary told me that during his appointment he had explained how anxious he was that the Zepatier might not have been successful. It is understandable that he feels like this given the Interferon treatment in 1990 was later found to have failed. However, Dr Bhati, who was sitting in an adjacent room, out of sight of my husband, reassured him that the Zepatier would have worked and said that she was more likely to have liver cancer than Gary. Although he requested a repeat fibroscan for reassurance, Dr Bhati said she would not offer this, and it would have to be arranged through Gary's GP. My husband found her attitude to be flippant and humiliating. He was cared for during this appointment by Pauline Kua, who had to go back and forth between the consulting room and Dr Bhati's adjacent office, to liaise with Dr Bhati: Dr Bhati did not even come into the consulting room to speak to Gary directly, instead speaking through an open door. During this consultation Dr Bhati twice asked my husband whether he was going to sue Warrington Hospital for what has happened to him. Both myself and my husband are appalled at the attitude she displayed throughout this consultation.

35. Financially, I had to take on the role of breadwinner in our family which has meant I have had to bear the main responsibility for financing our mortgage, paying for private child care and paying the household bills throughout most of our marriage. I had to become the main insured person for our mortgage and we have never been able to move house because this would have involved telling any mortgage company about Gary's condition, as described in Gary's statement. I always felt that I had to get the mortgage paid because once Gary was gone at least our son and I would have a roof over our head. We made our life very small,

paid off our mortgage and didn't move house so that things were easier to handle. Until Gary's second diagnosis of HCV in 2018 I had sort of accepted things, but now I feel angry and resentful again.

36. If I had been able to study for a degree, as my company encouraged me to do many times, my earnings would have been substantially higher and I would have been able to command more respect in my workplace. I worked in engineering, a traditionally male dominated environment and things would have been easier if I could have gained qualifications to prove I was as good as the men. However, I had neither the time nor the energy to commit to studying at that level. I will always regret not being able to achieve this ambition but it would have been the card that brought the whole house down.

Section 6. Treatment/Care/Support

37. Gary did face difficulties in obtaining treatment for his HCV in both 1990 and 2018, and this is set out in his statement.

38. Neither Gary nor I have ever been offered any counselling or psychological support in consequence of his infection. I have suffered with depression for many years and have only ever been offered anti-depressants rather than any counselling.

Section 7. Financial Assistance

39. Gary's statement sets out the financial assistance he has received, and the difficulties he has faced in accessing this assistance. As described in his statement, I have had to assist him in accessing financial support by searching online for the correct scheme to contact as Gary had been told to contact the Skipton Fund when in fact it no longer existed. I have also had to contact the EIBSS for him on many occasions because the

process is so bureaucratic, time-consuming and frustrating that he has been ready to give up. I have not found the staff at the EIBSS to be particularly helpful.

40. Gary had to provide medical evidence in order to obtain financial assistance from the EIBSS. I found the lack of co-operation by both the consultant and his GP astounding. It was only when Gary asked both his consultant and GP to provide a letter explaining why they could not provide the information he needed so he could show it to his solicitors that both became more cooperative. Even so, Gary still had to pay his GP a fee of £24.50 to sign the form (a total of 11 words, including the date). The EIBSS also would not provide any assistance whatsoever to help Gary obtain the necessary medical records. I could not help but conclude that all involved were deliberately slowing the process down as much as possible and to some extent discouraging us from pursuing the matter further.

41. It was so difficult to obtain copies of the letters we did manage to acquire from Gary's records that I believe there must be more evidence associated with the infection that is missing from his records.

42. Gary could not apply for top up payments from the EIBSS because our son still lives at home and his salary would be taken into account when means testing payments from the EIBSS. I find it hard to accept that our son's salary should be taken into account for the purposes of means testing. The payments Gary receives should not be regarded as state benefit. I believe these payments are unique in their purpose and should not adhere to other state benefit rules in any way. However, on 30 April 2019 the government removed the need to apply separately for income top-up (means testing) so he receives the annual non-discretionary payment of £18,458 (Hepatitis C Stage 1). If the Inquiry had not influenced this decision we would currently be unable to pay all of our

household bills and buy groceries. We thank the Inquiry for bringing about this change but the payments are still too low to provide a reasonable standard of living.

43. I have not received any financial assistance from any of the Trusts and Funds myself.

Section 8. Other Issues

44. I believe my husband has never been told the whole truth about his condition or its cause. Until he met the special-care nurse at Warrington General Hospital in 2018 I believe both of us had been 'kept in the dark' for nearly five decades (47 years).

45. I hope the Inquiry process is a transparent one. I wish to know which Health Minister (serving during which government) sanctioned the use of untested blood from high risk sources. The inquiry needs to understand whether this decision was purely a financial decision. I also wish to know why the use of this blood continued for many years. Were the same sources used for blood supplied to private hospitals? I wish to know who signed off on the use of this blood. Who, when, why?

46. I hope the Inquiry will result in all infected and affected people receiving:

(i) individual, written apologies;
(ii) adequate, non means tested financial compensation;
(iii) a Blue Badge, as per the Blue Badge Scheme used in Ireland;
(iv) written assurances that a similar tragedy cannot happen again;
(v) a comprehensive action plan detailing the preventative measures to be taken by the Department of Health and the NHS to ensure this does not happen again.

47. One of the main things I would like to see as a result of this Inquiry is a change in attitude within the NHS towards HCV and its sufferers. If people are anxious about their HCV, its treatment and possible recurrence, then NHS staff must behave professionally and sympathetically and follow-up should be offered as a matter of course.

Statement of Truth

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

Signed GRO-C

Dated 16-10-2019