LF/V1850190

Witness Name: Eileen Patricia Dyson
Statement No.: WITN2130001
Exhibits: Nil
Dated: 8th January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF EILEEN PATRICIA DYSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Eileen Patricia Dyson, will say as follows: -

Section 1. Introduction

1. My name is Eileen Patricia Dyson. My date of birth is GRO-C 1958. My address is known to the Inquiry. I live with my husband and we have been married for over 38 years, his name is Kenneth John Dyson and he has now retired from teaching. We have two children, Keith who was born in 1988 and Julie who was born in 1989. Keith is studying for a degree in engineering and Julie is a Chartered Accountant. Prior to becoming too ill to work, I was employed as an International Tax Manager advising expatriates on global contracts and was qualified in US tax compliance in accordance with IRS regulations.

2. I intend to speak about my infection of the Hepatitis C virus following a blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

Section 2. How Infected

3. I was infected with hepatitis C through a blood transfusion.

4. When my son Keith was born on GRO-C 1988, it was a very difficult birth and I was left in labour for 36 hours with little care from the midwives on duty. It was only when it was realised that the baby was in distress, a doctor carried out an emergency Caesarean Section. Following this surgery, I was given three units of blood. This all happened at Bellshill Maternity Hospital. I do not know the names of any of doctors that treated me. After the transfusion for the birth of my son Keith, I became very sick. I was transferred to an Infectious Diseases Unit at Monklands Hospital and put in an isolation room. I was separated from my baby son; I was kept in isolation for the first week of motherhood while nurses attended to my baby son and I was never given the chance to cuddle or feed him until I was discharged. They did not explain what was wrong. They said that I had an infection and I could not be near other mothers or babies. The doctors and nurses were deliberately evasive with me and did not tell me what infection I had. The whole experience left me traumatised.

5. Then in May 1988 I was subsequently admitted on an emergency basis to Hairmyres Hospital in East Kilbride. I was haemorrhaging because those responsible for my Caesarean Section left a section of the postpartum in situ. I was given two more units of blood. A very distressing experience under the care of the NHS.

6. In February of 1989, I went to Monklands Hospital as an outpatient to have a Barium Meal test because I was still unwell. The results showed an

irregularity in my oesophagus that needed further investigation. So, on the same day as an outpatient they carried out a biopsy on my portal vein through an endoscope. During this procedure my hepatic portal vein was punctured. They didn't notice and sent me home. Within 24 hours I haemorrhaged again and was rushed back to Monklands Hospital and had emergency surgery to stop the bleeding. During this, major surgery on my liver I was given 16 units of blood. The consultant that carried out the procedure was Mr McKenzie. I was placed in intensive care and after a few days I was also told that I was pregnant. They said that the contraceptive that I had been using, had not been effective because I was so ill. Throughout my second pregnancy I was monitored on an outpatient basis, by three hospitals (Bellshill Maternity, Monklands Hospital and Hairmyres Hospital), all taking blood samples routinely.

7. On GRO-C 1989, I gave birth to my daughter Julie she was born naturally. After Julie was born, I remained very unwell.

8. On 5th February 1992, my GP referred me to Monklands Hospital again. I saw a Mr GRO-D he had been responsible for my gastroenterology care since 1988. He was a consultant surgeon and I was referred to him due to my high levels of pain, restricted diet and chronic fatigue. He decided to remove my gallbladder and within days I was readmitted to Monklands Hospital with acute pancreatitis cause by debris from the gallbladder surgery that had not been drained away properly.

9. It was after Keith was born that I started suffering from fatigue and pain. I didn't know if that was just normal after a Caesarean Section so it was difficult for me to really know. My GP said maybe it was ME (myalgic encephalomyelitis) or glandular fever or something. But no clear diagnosis was determined.

10. The fatigue I was suffering after Keith's birth was crippling. I had little muscle strength and was suffering from brain fog as well as sickness and nausea all the time. I had a lot of joint pain. Pain relief worsened certain

symptoms. I could not take Paracetamol nor any regularly prescribed painkillers as my liver was already compromised. Sometimes my pain levels were so high I would be given morphine. In the episodes of severe pain, I'd be given pethidine and morphine while at home, which I now know can be very dangerous.

11. I was very reluctant to take any painkillers on a regular basis that would cause drowsiness or disorientation as I was responsible for two babies that needed my care. I had no support while my husband was at work despite health visitors being well aware of my limitations and lack of family support. Through a request by my GP, Social Services carried out an assessment and only offered to prepare a meal for me which was pointless as I could not eat properly. They said they could not offer any support for the children so, my husband and I relied on the kindness of my neighbours when I was in hospital. It would take three years before my children were given a nursery place of three hours a day.

12. Most days and nights I would spend in and out of bed. When the babies were young (an infant and a toddler) and my husband was at work I would keep them beside me in bed if I wasn't able to sit up. It was very difficult and distressing when symptoms of pain and vomiting were bad because I didn't want my children upset by witnessing my suffering. But this was a common occurrence.

13. I was never warned of any risk in having blood transfusions. There were a few times doctors said I was anaemic and they thought that giving me blood was a good solution. I think I may have been given other blood products as well as I remember times, I received blood and they mentioned plasma so I don't know how often I received it.

14. I was diagnosed with Hepatitis C virus somewhere between 25th November and 3rd December 1993 when I was admitted to the GRO-D GRO-D to investigate why I had remained so unwell since my

children were born. I endured multiple tests each day, but staff didn't say what each test related to.

15. I was then called back to an outpatient clinic a few weeks later. This would have been the January of 1994. I believe that the consultant was Mr A. J Morris. He was consultant of gastroenterology at GRO-D Unfortunately, my husband has just gone to attend to the parking meter when I was taken into the appointment so I was on my own. Doctor Morris said, "I am pleased to tell you lots of the things we were looking for you did not have but you do have Hepatitis C virus and this is why you are experiencing the symptoms of pain, sickness and fatigue." I had never heard of Hepatitis C so I asked him, "How do you get Hepatitis C?" He said, "Drugs use where needles are shared among drug users or numerous sexual partners." I explained that my husband and I had never taken drugs and we married when we were in our early twenties so we hadn't any other partners. He did not respond to this. My husband was shown into the room and I explained to him that I had Hepatitis C. Doctor Morris said that there was a treatment called Interferon which had little effect. He did not offer me any treatment. I asked him what I could do and he said nothing. There were other doctors in the room at the time, who were not introduced to me and I continued to insist that it did not make sense that I contracted the virus in the ways that were suggested. They hinted that some people get Hepatitis C through blood transfusions. I asked how I could find out if my blood transfusions were infected but they completed evaded the question and only stated that it was now about monitoring the virus so they could look for indicators of cirrhosis or cancer and explained that I would have to attend the Liver Clinic every three months for the rest of my life. I was not offered any support or counselling from Mr Morris or his colleagues. I was absolutely devastated. I left and completely broke down in tears. I was so afraid I would not be able to care for my young family and I would die prematurely.

16. I definitely feel they should have told me earlier about my diagnosis. Each day I was an inpatient at GRO-D in December 1993,

there were approximately eight consultants around my bed. They were all asking very detailed questions. Having been in hospital so many times before, I knew the normal procedure consultants and junior staff carry out during their hospital rounds each morning. This was not normal. By the third day they wouldn't talk to me. I asked them if they could tell me what they had established and just one consultant stayed behind and said they were testing for something that they were following up on. I asked why there were so many consultants and they told me I was an interesting case. Another consultant came back and examined me, only saying I was a fascinating case. I had never experienced anything like it. It was not normal treatment. Looking back now, I feel that they knew I had the Hepatitis C virus at that point. It obviously wasn't until the January 1994 that I was told.

17. I do feel that they should have never told me I was infected with the Hepatitis C virus when I was on my own at the outpatient's clinic. I was by myself since my husband had gone to check the parking meter. I do feel that they failed in their duty of care. They clearly knew that it would be distressing and should have waited until my husband returned as it was only a few minutes.

18. When my husband did return, I don't remember them telling us anything about cross infection and how others can be infected. There was no advice given about my husband or children. Really there was just no duty of care. There was nothing to protect my family. I felt that they were hurrying us out of the hospital. There was such unease in the room and they clearly weren't comfortable dealing with the doubts we were raising regarding the source of the infection. It definitely did not seem that they were prepared for any blame to rest on the NHS.

19. In retrospect I now realise that the treatment I received from the NHS since the birth of my son until I was diagnosed with the Hepatitis C virus caused me untold suffering which would now be recognised as PTSD.

This would also apply to my husband. Sadly, this was not the end of our suffering.

20. I knew I had to do my own research to find out what had been done to me while in various hospitals receiving treatment. I contacted the Scottish Blood Transfusion Service to get the batch numbers of the blood I had received. The first phone call, the person I spoke with did not give their name. I asked for the batch number and the person was very unhelpful and basically just rude and abruptly ended the call. I phoned back a few days later to get someone else and they said that they didn't keep that information and there were no records. They also said there was no record of me ever having had a blood transfusion. It was nonsense and they were totally uncooperative and obstructive. I was clearly being lied to.

21. I also contacted my lawyer at Ballantyne Copland in Motherwell to see if he could find out what blood products I had been given. He said there was no point in trying to take any action as there was no legal aid available for patient's infected with Hepatitis C by the NHS, to take their cases to the courts. He said the law firm Thompsons in Edinburgh were taking a test case to court, which would take years and to proceed on my own would be costly and pointless. He said that although it was not easy to accept there was nothing legally, I could instruct him to do. I felt completely abandoned, there was no other avenue of enquiry or redress. I would now have to tell my husband that we would have to face the consequences of me being give blood infected with the Hepatitis C virus, alone.

22. After my diagnosis, I was back at GRO-D as an outpatient every 3 months. This was at the Liver Clinic and most people attending were drug users. This was a complete culture shock for me. I remember being in the waiting area with my children and being afraid for my children and myself. Nurses and doctors were not compassionate to my situation, I was treated as though my infection was due to my own conduct, and this was very traumatic. At no point did they offer any support. It got to one point where I broke down and I said to one nurse

"You're assuming I am a drug addict" and they admitted they were and that there was no support for people infected by a blood transfusion. The nursing care was absolutely non-existent, it was brutal and heartless. This would continue at GRO-D for seven years.

Section 3. Other Infections

23. I was infected with hepatitis C virus.

Section 4. Consent

24. In terms of consent, I would say I was tested without consent, knowledge or been given full or adequate information. I also feel I may even have been treated for research purposes. I feel it was research for their own career development. They were working as a team and not all the doctors were from GRO-D One doctor was visiting from Africa and they asked if I had spent time in Africa which I had not.

25. When I was first diagnosed in 1994, I was told that interferon was the only treatment available. I was told that it was an injection every day for a year and it would confine me to bed. I was told the success rate was very low. I believe I was told by a GRO-D and a D GRO-D I was told I had the wrong genotype. They said if I got the treatment, I would be very sick and it would fail. It was compared to chemotherapy. It would not be until 2015 that I would finally receive treatment.

26. After seven years, at GRO-D I asked for a move to a hospital closer to home as I was too ill for the travelling and I was transferred to Strathclyde Hospital Motherwell on 6th September 2000. There I was under the care of Dr Crofton whose approach was generally about monitoring the pain and fatigue. I still had blood tests every three months and for the next seven years endured severe pain, fatigue and serious restrictions to my diet which affected every aspect of my life and that of my family.

27. In 2007, my health deteriorated drastically and my prognosis was very poor. I had repeated jaundice and blockages in my bile ducts. I had emergency admissions on 6th January 2007 and 1st February 2007 to 9th February 2007. In August 2007 while on holiday in France my bile ducts became blocked and I had to go into hospital for emergency treatment. Even though there was a language barrier in explaining procedures and scans this was the most compassionate supportive treatment I had ever had. Every member of staff treated me both physically and emotionally with gentleness. Consultants conveyed genuine sadness and concern that I had been infected by the Hepatitis C virus through blood products. Even though this was a very stressful experience to be in hospital abroad it showed me that over the years I had not received the medical treatment, care and support I deserved.

28. On my return home I gave the French consultant's scans and reports outlining what further treatment I needed to Dr Crofton at Wishaw General. Three stents were inserted on 13th August 2007, 28th January 2008 and 21st July 2008, and they all failed. Each time there was a blockage I was placed on a waiting list unable to eat or drink in unbearable pain and losing about a stone in weight each time. I was aware that the blockages had created a life-threatening bacterial infection requiring the administering of powerful and aggressive antibiotics, so to leave me on a waiting list with no medical supervision was reckless in the extreme.

29. By September 2008 I was getting more and more worried by the poor quality of life I had and the complete lack of care and I thought I may die. I felt nothing was proactive and everything was dealt with on an emergency only basis. There was no treatment plan. So, on the 16th September 2008 I contacted the British Liver Trust and asked if the treatment I had received was acceptable and they said it was absolutely not and I should seek a second opinion.

30. In September 2008 I went to my GP's surgery which is the Orchard Medical Surgery, Motherwell. I asked Dr D. A Barr to write a letter to the Liver Unit at Edinburgh Royal Infirmary, which he did.

31. On 13th October 2008 at Wishaw General Hospital Dr Crofton inserted a larger permanent stent into my bile duct.

32. In October 2008 I attended the Liver Unit in Edinburgh Royal Infirmary and met Dr C S Blair. She said she was concerned that I had not been offered any treatment for my Hepatitis C infection. I would be assessed for a liver transplant and she would obtain my medical records from the hospitals I had attended.

33. In March 2009 Dr Blair said that she had been informed that all my medical records had been destroyed at GRO-D. She was only able to gain a general summary from Wishaw General Hospital by telephone but no documentation. Dr Blair decided that going forward I should attend her clinic for the management of my care which I was relieved to do.

Section 5. Impact

34. The Hepatitis C virus had a very bad effect on my dental health and dental treatment was always very limited. Then in the period 2014/15 my dentist GRO-C in Hamilton refused to treat me any longer. Initially, I couldn't get an NHS dentist and I was told to go to a community dentist. I finally got a dentist in 2016 but only by paying privately.

35. The impact on my appearance was very dramatic as I went from being fit stong and healthy to being very unfit which greatly affected my self-esteem.

36. In terms of how I was affected by the diagnosis of hepatitis C itself, there was a huge stigma at the time and I was fearful of the consequences of

having it as a young mother. I was very afraid, for my children in case I would infect them and the same applied to my husband as well. I became isolated very quickly. When friends asked why I had been in hospital, I told them I had hepatitis C from a blood transfusion as I thought the right thing was to be honest with them. I think I was naive in thinking that they would be compassionate and supportive. I believe they associated it with the AIDS crisis of the 80s and very quickly I was excluded from many social events.

37. The impact on my career was devastating. When my health improved in 1995, I regained employment in International Taxation as an Expatriate Tax Manager but this period of wellness did not last and I became ill again in May 1996. I was off for six months and my employer GRO-C GRO-C in Glasgow, sent me for a private medical assessment. When the HR department told the partners that I had hepatitis C (which I had already disclosed on my application form) they refused to give me a staged return to work and made me redundant. It was made more distressing because there was adequate work and a new member of staff from Edinburgh quickly took up my role once I was discharged. There was no confidentiality and I was completely ostracised.

38. I was never able to return to my profession as each management position which arose required a medical which I was told informally, would not accept an applicant with the Hepatitis C virus. It could be equated to a prison sentence. This caused me great sadness, anxiety and suffering. In 1996 my career aspirations were to become an Expatriate Tax Partner. There was an inference that my salary would have been around £240,000. There was a likelihood of even that increasing. When I was working, it would have been automatic to send my children to private education. Had I been able to continue in my field of work this would have been something I would have done. Instead my only income was incapacity benefit and today I have no pension fund or personal investments. So, I lost my health, my career and financial security throughout my adult life and now as I face old age.

39. The impact of being infected with the Hepatitis C virus is that it has always prevented me from securing a mortgage, and attempting to purchase life insurance or travel insurance has always been very expensive or declined.

40. The impact upon my husband has been a life of worry and distress that continues to be a very heavy burden to carry throughout his life. It has and will continue to undermine his health and well-being and definitely limits his life choices. His career as a teacher was shaped and restricted by his carer responsibilities. In his retirement he continues to suffer from the injustice of what has happened to his family and himself.

41. In terms of the impact on my children's health and wellbeing and their school performance, I do feel that instead of a carefree childhood and the freedom to enjoy their teenage years and student years at university. They lived with the constant worry of having a very sick mother who may die. This was further compounded, when they were old enough to understand that the cause of their mother's ill health could have been avoided and so their lives are blighted by the scale of the injustice that has shaped and impacted negatively upon their lives

42. The impact on my ability to attend Church has had a profound effect on my spiritual care and wellbeing as a practicing Catholic. There were long periods when I was too ill to attend Church.

43. The impact on holidays with the family meant that too many occasions holidays were cancelled on the day of departure or mid-way through a holiday.

44. The impact of the aforementioned experiences of the last thirty years on my mental health is in reality beyond any narrative I can provide. Words are inadequate, they fail to convey the whole truth, and by this omission the enormity of my pain and suffering remains hidden and indescribable.

Section 6. Treatment/Care/Support

45. My GP mentioned the pain clinic at Wishaw General Hospital. This was situated next to the mortuary which hardly felt appropriate. Specifically focussed on pain relief for chronic illnesses, I'd hoped they would offer practical solutions but they did not. Infact the person responsible asked if I wanted to run the meeting which certainly was not beneficial for me in terms of support.

46. I phoned the Hepatitis C Trust but there was no support in Scotland. Even online with Scottish Infected Blood Forum and Haemophilia Scotland, there's nothing practical in terms of directing you to any advice about how to deal with what was going on. There was no counselling service. I feel that what was offered by the NHS and more widely was and continues to be fully inadequate.

47. I started on the Harvoni treatment in November 2015 to cure my Hepatitis C infection. Dr Blair explained that Harvoni was brand-new and because I was not covered by the Health Board in Edinburgh, she wrote to a colleague asking if I could get treatment from the Lanarkshire Health Board.

48. In terms of the symptoms I experienced while on Harvoni, I felt amazing for the first couple of weeks but by the fourth week when I had to go back for blood tests I could hardly walk. The nurses were shocked when they saw me. I was very ill for the remaining weeks of the treatment. I suffered from very bad headaches and weakness. The symptoms were very debilitating.

49. One aspect of the criteria to qualify for the treatment, was a psychological evaluation. I was told that this psychological evaluation was because the treatment cost a huge amount and they were worried about people backing out in the middle of treatment due to symptoms or lifestyle. After

the various assessments I was told I would receive the treatment of Harvoni. This evaluation process took eight months.

50. Prescribing the Harvoni treatment was difficult. The pharmacist wasn't sure how to administer it to me and because it was expensive, they would not give me the full course at once and I had to get it in two stages.

51. The Harvoni treatment was successful and on 27th June 2016 it was confirmed that I was no longer infected with the Hepatitis C virus.

Section 7. Financial Assistance

52. In 2005 at Strathclyde Hospital Motherwell, Dr Crofton told me about the Skipton Fund and said I should apply to the fund as I had got Hepatitis C Virus from contaminated blood during my blood transfusions. This was the first time a medical member of staff admitted the role of the NHS in relation to my infected blood. Dr Crofton supported my application and I received a payment from the Skipton fund of £20,000 on 4th October 2005. I did not receive anything else from them.

53. I received a sum of £30,000 in December 2016 from Scottish Infected Blood Support Scheme (SIBS). In December 2018 I started getting monthly payments of approximately £1500 from the SIBS after completing the appropriate application forms.

54. With regards to the Caxton Fund, their application process was a wholly and unnecessarily humiliating means test. I applied for educational assistance but instead they put me in touch with a phone service called Pennywise, which was shockingly inadequate, giving advice on managing your money. After months of waiting I received nothing and no apology for the offensive and degrading way I was treated.

Section 8. Other Issues

55. With regard to the final report of the Penrose enquiry, I was surprised by the lack of rigour and found it incredulous that the legal team involved in its construction was willing to publish such a flawed document.

56. Finally, it must be noted that no witness statement I can provide, can fully convey the scale of trauma and grief my family and myself have suffered and continue to suffer every day.

Statement of Truth

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

Signed GRO-C

Dated 26th March 2019.