Witness Name: Kenneth Dyson
Statement No.: **WITN2129001**
Exhibits: N/A
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KENNETH DYSON

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

I, Kenneth Dyson, will say as follows: -

Section 1. Introduction

1. My name is Kenneth John Dyson. My date of birth is GRO-C 1958. My address is known to Inquiry. I am retired and prior to retirement I was a maths teacher in secondary school. My wife and I got married in 1980 and we have two children. We have Keith, who was born on GRO-C GRO-C 1988 and Julie who was born on GRO-C 1989. I am giving this statement in relation to my wife Eileen Dyson who was infected with hepatitis C following a blood transfusion. In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

Section 2. How Affected

2. My wife required a transfusion after our son Keith was born. She had this at Bellshill Maternity Hospital. I do not know the names of the doctors who treated her. I believe she may have received the transfusion after the birth itself due to this being a C section birth. They told her that they had broken a catheter and it had become infected. She was violently sick during that day. She was moved from Bellshill Maternity to the Infectious Diseases Unit at Monklands. I found out when I called the next morning and was told that they had moved her. They said she had an infection but we were not told any more than that. They had said to Eileen that she was a danger to other mothers and newborns if she stayed in Bellshill. The Unit in Monklands was awful. I had to speak to Eileen through a hazard protection window. A few weeks after Keith was born, my wife was admitted again because she haemorrhaged.

3. In February 1989 she was told that she was to have a biopsy because they had seen a shadow in a scan. She was sent home. The next day she started vomiting blood. An ambulance took her to Monklands Hospital where they admitted her to a ward and gave her milk. During the night a patient found Eileen on the floor and got the nurse. Eileen was vomiting blood more heavily. She was taken to theatre. I was told to stay in a waiting room. I was there for several hours. Occasionally a nurse would appear asking if I wanted tea, then a doctor came to see me. He said that they had to find what was causing the bleeding and try to stop it. I think he said that she had to be given 20 units of blood. Eileen was still in intensive care for hours and this was quite traumatic as I was on my own and had real difficulty in comprehending what was happening. I recall that a Dr McKenzie spoke to me to say that her condition was serious but stable because he thought that he had managed to stop the bleeding.

4. At no stage did they say that there was any risk with my wife having a blood transfusion.

5. My wife was eventually diagnosed with hepatitis C but we did not know about this until a few years after.

6. Throughout this time my wife started to become constantly fatigued and generally quite unwell. She struggled at work and did have a high-powered job working as a US tax consultant for expats. Her symptoms were flulike in nature. She suffered from terrible fatigue, pains and there was obviously something wrong with her. She was attending hospital regularly. We did not know that she was being tested for hepatitis and it came as a complete surprise when she was given the diagnosis at GRO-D. I was parking the car and had left her in the waiting room. When I got there, I discovered that a Dr Morris had already told her. He appeared very blasé, so much so that I did not get the feeling he was telling her something so serious.

7. In terms of the information that was given to my wife about her infection, there was not much given at all and we did not realise how serious this was. All he told her was that she had hepatitis C and I cannot remember exactly how he said you could get it but there was a clear impression given that it could only have been transmitted sexually or it could have been given through intravenous drug use. He implied that one or the other of us had extra marital sex. It was almost still treated though, as a non-event and I did not realise the serious implications of the infection.

8. I do not believe that adequate information was provided. Eileen told him that she did not understand how she could be infected through the routes he had suggested. She said that she had had several blood transfusions and asked if that was a possible way of being infected. I remember him saying something along the lines of that 'At least Eileen is still here' and 'She might have died had she not had the transfusion'. There was a definite feeling of unease and evasiveness at this point of

the consultation. This diagnosis would have been in around December of 1993. I believe this doctor suggested interferon treatment but there was no substantial information.

9. The gravity of what was being told to Eileen, I feel that they should have waited until I was there as well. She was told on her own. When I came back in to the room I didn't quite get that it was serious and there was no sense with them leading us through it. At the time it was sort of equated with the AIDS crisis of the late 80s. I recall them saying there could be up to 15 years before Eileen would get full symptoms of cirrhosis or liver cancer. We both then felt the notion of there being a timer on things. We were always waiting for that starting gun. I was not offered any testing.

10. In terms of the advice given to us about infecting others, they pretty much just told us that we should not use the same toothbrush.

11. My wife got the impression that her diagnosis of having hepatitis C was already in her medical notes. The way the doctors said it was as if was already a known thing, as if it was a foregone conclusion at that point. As such, I believe that we should have been told earlier as we are not really sure when the medical staff knew, prior to when we were told.

12. I do not remember what they did in terms of any tests on Eileen's blood. She would often go to hospital by herself. When she was diagnosed, she went to a clinic where there were a lot of drug users with her. I know she felt like they assumed she was using drugs. The people there would strike up conversations about drug use and I couldn't stand the thought of Eileen having to sit and listen to those conversations. I recall at one stage someone made a remark at Eileen that if she wasn't a drug user and if she was monogamous, then her husband must have been playing away and that's how she would have been infected. It felt like they were trying to skew any blame away. The NHS never accepted

any blame. It was very upsetting and I believe we got her consultant changed to a Dr Crofton who has since passed away. He was based at Strathclyde hospital.

13. There was never anything said about any other members of the family possibly being infected. I was never tested or asked about being tested. The only time it came up was when I asked my GP during an appointment some time near the end of 1996. I had been increasingly more stressed and went to the doctor. As part of a general conversation, I mentioned Eileen being infected and asked whether I should be tested. The doctor said that I could get tested but I should think very carefully about the consequences of a positive test result. She said that if I knew I was positive then I would have to declare this on any applications for mortgage or insurance policies. She said that if I didn't know then I could make applications. Eileen could no longer get life insurance or any travel insurance.

14. When the children were young, Eileen was in hospital a lot. I believe she was in hospital for around the time the children were two years old. Around that time we noticed the fatigue that she was suffering as well as the brain fog.

Section 3. Other Infections

15. My wife was infected only with hepatitis C.

Section 4. Consent

16. I'm not sure how the hepatitis C diagnosis came about. I have no memory of the doctors saying there were going to test for this. It may have been that Eileen was tested for hepatitis C without her explicit consent. I believe you have to be looking for hepatitis C to find it. They

must have been targeting hepatitis C in the test they did. I do not think they ever said that they were going to test for hepatitis C. I do believe that Eileen may have been tested without being given full information.

Section 5. Impact

17. As a mother, I feel that her diagnosis devastated Eileen. Her symptoms did not help this. She was devastated that she could not look after the kids the way she wanted to as she was often in bed a lot. She always did look after them well when she was capable. It was different for her and it was difficult. She found playgroups and things like that quite difficult. People found out about Eileen's hepatitis C as she did not keep it a secret and friends would not let their children play with Keith and Julie because of Eileen's diagnosis. They knew because she was often having to go to hospital. In the end the children had to move playgroup.

18. Eileen became isolated because she was not able to do things with her friends. She would make plans and then not be able to see them through because of her fatigue. It was chronic and I think people lost interest and concern in her. A lot of people she knew gave up on her. People showed concern at first but they gradually fell away into the background because Eileen's condition never seemed to improve. It seemed that they only wanted to hear good news and could not cope with a person who was chronically ill. She would often make plans and then just suddenly have fatigue or would be ill and would just simply not be able to go. This could happen even if people were waiting outside on her, she would suddenly have a bad turn and she would not be able to go.

19. Physically, Eileen was unreliable, through no fault of her own. She could not say with any confidence that she would see someone on someday or see something through. She would get wiped out and not able to do anything.

20. As I have said, I was a teacher and Eileen was actually on a much better salary than me in her role as a US tax consultant. Her earning potential was amazing. I believe it was in 1996 that Eileen had to stop work completely.

21. In terms of the medical complications that have arisen as a result of Eileen's hepatitis C, there have always been underlying issues with her liver. Eileen does have issues with her bile ducts as well.

22. I recall when we were on holiday in France in 2007, Eileen had to be admitted to a hospital, and that is when they found out about her bile duct condition, it was never picked up on in any hospital here. She'd had numerous scans with every type of scanner. However, in France, within minutes of carrying out a basic ultrasound scan they were able to identify a blockage and tell her what her condition was. She was told that there were only two hospitals in France where they could operate, one in Paris or one in Dijon. Since this would involve an air ambulance, we had to decline because of the type of medical insurance that Eileen had access to – none. The treatment, both medically and patient care by every single level of staff in the French hospital was markedly better than anything we had encountered in Scotland. So we were given the results and records on a CD and they gave Eileen medication (a very painful antibiotic injection) for our journey home. She was at high risk of septicaemia. I drove for seventeen hours to get back home and took Eileen straight to A&E in Wishaw. We brought back this CD and it was given to Dr Crofton who operated on Eileen putting stents into the parts of the bile duct identified by the French doctor.

23. Eileen has always been getting tested for cirrhosis or cancer of the liver. I am not aware of Eileen having cirrhosis but I am aware of there being some scarring on her liver. As far as I'm aware, this is not any level that her doctors are concerned about at this stage.

24. My wife was treated for hepatitis C with a drug called Harvoni which she started in late 2015. This was her first treatment for HCV. The liver nurse, who I do not know the name of, said that she was the last one to get it due to them cutting funding for this treatment.

25. I believe they tried to get Eileen to go on interferon 10 or 15 years ago but they knew that for her genotype, that it would not be successful. No one had told her then of the different genotype. I believe it was known then that interferon would have a 20% chance of success with Eileen's type hepatitis. I believe she only found this out through her own research.

26. The Harvoni treatment was successful. After this treatment she was clear and non-active and still is now. Her level of hepatitis is below a measurable quantity. I believe that certain scanners can't read below a certain level and it is below that level. The virus is no longer active.

27. The consultant now is a Dr Blair at Edinburgh Royal infirmary and that's the best one I think Eileen has seen. She is a perfect model of how the profession should have dealt with Eileen's condition. She has lots of empathy and Eileen feels that she has been treated professionally, as do I. I believe that Dr Blair wanted to give Eileen a liver transplant but they have been holding back until she was non-active.

28. One obstacle Eileen faced was that she could not get Harvoni while being treated in Edinburgh. Due to funding constraints across Health Boards Eileen had to go to Monklands Hospital to be treated. She was really reluctant to go to Monklands because of their past history. It was a Dr Duncan there, who was very much just there to rubberstamp the treatment. Dr Duncan was not as involved as Dr Blair. She was present at one meeting with us when Eileen was trying to get them to reverse the decision to change her Liver Nurse. It had to get to the stage of an argument. They had changed the liver nurse to a man who was awful.

He claimed to have no notes and wanted to start blood test all over again. Giving blood samples is really difficult for Eileen and since she had gone through this only about a week before she did not see the point. When asked why he said that he just did. Dr Duncan and her team met with us but we would not agree to the new nurse starting all over again because he had no notes. Eileen managed to contact the original Liver Nurse herself and her treatment continued as before.

29. The Harvoni was in the form of tablets. This treatment did involve having to have blood tests every couple of weeks. I believe this was to ensure that the treatment was still working.

30. In terms of the symptoms Eileen faced while on Harvoni, she was nauseous and had headaches. Whatever it was, it was worth going through to become non-active.

31. I think one of the biggest difficulties faced was just finding a consultant who would sit and talk properly to us, everyone we saw, it was clear that they wouldn't read the notes in advance and the only one who really did was Dr Blair at Edinburgh Royal infirmary. She took an interest where others didn't.

32. In terms of other treatment, no there was no other treatment this is the only one. We asked for Dr Blair because of how much Eileen trusted her, but because of the financial implications for Lothian Health being made and because the treatment was no longer available in Edinburgh Dr Blair then contacted Lanarkshire Health Board.

33. In terms of how Eileen has been treated when she has been in hospital and if her hepatitis C status has affected her treatments, I would say that this has been a major thing any time that Eileen has been in hospital. She has to go quite often because of issues with her bile duct. On her file we noticed there was a big massive red X and stickers saying that she is infected. Doctors or staff nurses would see this and

Eileen felt like she was treated like a leper. It has been like that for years. In stark contrast however, we had to go to A and E recently because Eileen had an emergency after what appeared to be another bile duct blockage. The duty doctor who was seeing Eileen dropped a cotton swab that had blood on it. Without giving a second thought, she simply picked it up and put it in the waste. She was not wearing gloves. There was none of the usual sense of ultra-caution that we have become accustomed to seeing. We were certain that this is due to Eileen's status as having non-active hepatitis C. It was so obvious that before this Eileen felt as if she was treated like toxic waste.

34. Eileen's condition has affected her access to dental treatment. The dentist that she had been going to for years, GRO-D who owns the GRO-D dental practice in Hamilton, said they would not treat her anymore. We all stopped going to this dentist as well when this happened. She had been to that dentist for years but could not take any medication in terms of her teeth because of her liver not metabolising them properly. They said that her case was becoming too difficult. Eileen tried for months to get treatment and the NHS sent her to a clinic in East Kilbride. The clinic in East Kilbride tried to force her to have all her teeth taken out and give dentures.

35. In terms of Eileen's social life, I would say that she lost pretty much all of her friends through the years. Part of this was down to not being able to follow through on plans because of her health. Prior to her symptoms and diagnosis, she would see her pals on a regular basis. We had kids parties and things like that and she would socialise with the other mothers. This all seemed to come to a halt when the fatigue started. This involved her having to leave at short notice or not show up due to the fatigue. Eileen puts on a brave face about it, but over the years she has gotten upset over this.

36. Due to Eileen not working, it did have an effect on what we could do as a family. We wanted to be normal and try and get away on holidays and things during summer, but we could not always stay long anywhere before Eileen would take unwell. Mentally, it was awful losing her job. She was very good at her job. Her condition has never affected her ability as a mother, she has always been a really good mother regardless of how unwell she has been over the years.

37. I have seen at my own work where people will ask about Eileen. After a while, people just don't want to hear about a sick person. People get fed up hearing about someone being ill and being sick all the time. I think people generally have an issue with understanding chronic conditions in the sick.

38. I retired in the summer of 2018. I taught maths to start with and then became head of Department. Eileen's condition deteriorated whilst I taught at St Aidan's in Wishaw. They were good with me at first with how I had to deal with Eileen's health. I had to put Keith and Julie into a council day nursery so that I could go to work when Eileen was in hospital. My boss would help picking up the children and things like that. It was hard running a department at school with everything else that was going on. I did have to get signed off with stress in 1996. I was off for a while and then put on Prozac which had serious side effects for me. It has left me with a legacy of unpleasant symptoms. I was off for around about five months. I was made the head of my apartment in 1995 and this absence during my tenure as Principal affected my chances of promotion after this. I ended up leaving there in 2005 after 20 years teaching at St Aidan's, to go work in West Lothian. I was the Faculty Head of Maths and three other Technology Departments. I do feel that my ambitions have been stifled by everything that has gone on. After being absent from work I felt that I was being treated as a malingerer and, as if to confirm this I was 'seconded' to another post in the Authority. During my secondment the post I previously held was advertised and filled. I was once a very well regarded and valued

professional. At that time, I felt that my career had ended and my name and reputation as an excellent teacher had been tarnished. I did have an ambition to become a head teacher. By the time I retired, I was earning just below £50,000. If I had gone on to be a head teacher, I could have earned around about £80,000. I have been paying a mortgage since 1981 and have no means of clearing it except by selling my home.

39. I would say that there has been little impact on my social life through Eileen's illness. This was only through choice and I believe because of everything that was going on, I stuck closer to Eileen. I do not see this as a negative though. I do not see friends as much as I used to but with the seriousness of what has been going on with Eileen, it does trivialise other relationships and it changed my priorities. Being sick for so long meant that sometimes Eileen would actually spend more time with the children than she would have done had she continued working.

40. With the children, I do not remember when we told them about Eileen's illness. We told them that their mummy was not well at first and we only really told them why when they were adults. It was only in the last few years we told them. We didn't want Eileen's condition to alter their lives. She was always home and unwell but they just really knew that she was not well.

41. In terms of how their school performance was affected, that is quite difficult to say. They are both clever and did well but they hated their schools. Had our financial situation been better, we would have sent them onto private school which were unable to do, because of Eileen having to stop working. Julie has gone on to be an accountant and Keith has just gone back to university to study engineering but he does not keep well himself. **GRO-C** **GRO-C**

42. In terms of the stigma, I do believe this did have an effect on Eileen's friends. From my perspective, I believe that they scarpered when they knew what she had. I do not know if Eileen told her employers but they may have just thought that the issues were down to her fatigue. I feel that Eileen's friends were perhaps ignorant about the condition and its ramifications. I do not know that for certain but that is how I feel.

Section 6. Treatment/Care/Support

43. In terms of the support offered, nothing of any value really. Eileen was shown a poster for a self-help group. She went to one meeting. She did not find this beneficial and found that people there were far too emotional. I think if she had gone back she'd have been destroyed over time. It was the opposite of enriching and would deflate her. I believe the type of support offered was wrong. What support was offered was inadequate. One of the difficult things that Eileen has had endure is having to go through the disability benefits system. For someone with such a strong work ethic this was really tough, but she always did her research and knew what she was entitled to. The frustrations and obstacles that were deliberately put in front of her were designed to make her give up. Having to go for medicals to prove that she has this illness and it is real has been soul destroying. 2 years ago, Eileen said stuff it to the disability benefits. She did have a disability car before this. The issue is the bureaucracy. She said she was having no more of it and she had this constant feeling that she was being doubted when all she was doing was being honest.

44. At no time has anyone from the NHS suggested that anyone else in the family should be tested for HCV. In 2015, when Eileen was undergoing her Harvoni treatment, I asked the Treatment Nurse if I should be tested in case I re-infected Eileen. The nurse was surprised that I didn't know, after nearly thirty years, whether I was infected. She agreed to take my bloods. My test came back negative.

Section 7. Financial Assistance

45. In terms of financial assistance, we did receive some money through the Skipton fund I believe. I believe it was Dr Crofton that mentioned this to us. Even though Skipton had been told by the doctors, we still had to prove that as well. I believe she had to go through hoops to get that. The blood transfusion service denied all knowledge of Eileen's own condition, which made things difficult. I think Eileen dealt with these applications.

46. Caxton was murder to deal with and I don't think she got anything through this. They were completely unsupportive. They told her they were there to give her money towards repairing things like a broken-down washing machine.

47. The new Scottish Infected Blood Support has started now. This is a monthly amount that is divided from a sum of £15,000 per year. I believe the funding applications were dealt with by Eileen.

48. I would say that the general financial assistance that has been offered has been insufficient. The new form was generally par for the course with these applications and they are all quite intrusive.

49. I think the issue has been a complete lack of joined up-ness with these funds. I have twice written to our MP in relation to what has been going on trying to get him to support the case for HCV victims. He never replied and never attended the Parliamentary Debate. I think an MP somewhere knows where the bodies are buried and that's what's wrong, I feel like there is a plan on their part to continue hiding things.

50. I recall there was something in the Cabinet minutes when John Major was Prime Minister, where he wanted to remove any use of the word 'compensation' when dealing with the Contaminated Blood issue. I believe that the amount of funding has probably been bogged down in

politics over the time. It's all been kept quite secretive and vague and I feel this was deliberate. All the other countries that have dealt with infected blood have dealt with it better. I remember that some Japanese officials had to kneel and apologise for what had happened and France jailed some of the perpetrators.

Section 8. Other Issues

51. I recall that there was something going on with Thompsons years ago and I am not sure of the full involvement Eileen had with this. I think that she ensured her name would be recorded as an infected person.

52. We asked the lawyer who did our first wills, and our own GP (Dr Sturgeon, I think) years ago about whether we should consider litigation. They both, independently, put us off pursuing anything. Saying that each other's profession would bounce it back and forth for years until it disappeared down a black hole or until we ran out of money. There was no Legal Aid to be granted to HCV claims so we were stuck.

53. We both gave a statement to the Penrose enquiry. It felt this was a total waste of time. Eileen went to the launch and was very upset by the reaction of the people in the room when the findings were announced. It felt like Penrose was there to make sure that the medical profession came out all right. They were there to absolve the medical profession of any fault. I do not think that the Penrose enquiry did anything for any of the victims of the infected blood scandal.

54. As an affected person I would like the following questions answered as a result of this Inquiry. (1) Why were medical records destroyed? (2) Why has only the UK not paid out substantial compensation like Ireland, France, Japan and virtually every developed country involved in the

scandal? (3) Which MP's or relatives of MP's were involved in the trading of contaminated blood products between USA, Italy and the UK? (4) What is the name of the person who signed the agreement to buy Blood Products from USA for the Scottish Blood Service? (5) How much money was involved in these transactions?

Statement of Truth

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

Signed GRO-C

Dated 5.9.19