Witness Name: Barry Fitzgerald Statement No.: WITN2819001

Exhibits: WITN2819002 -

WITN2819015

Dated: 12 August 2019

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FIRST WRITTEN STATEMENT OF BARRY FITZGERALD

Section 1. Introduction

- 1. My name is Barry Fitzgerald. My date of birth is **GRO-C** 1953 and my address is known to the Inquiry.
- 2. I have two adult sons, Ronan and Ruairi. I retired in 2008 and had previously worked as a delivery man for Royal Mail.

Section 2. How Affected

- 3. I am writing this statement in memory of my late wife, Jane Yvonne Fitzgerald, date of birth GRO-C 1961, who was infected with Hepatitis C ("HCV") through a blood transfusion in 1978.
- 4. On 11 August 1978, when Jane was 17 years old, she was given a blood transfusion of two units of blood at Royal Victoria Hospital in Boscombe, to treat an ectopic pregnancy. (WITN2819002). I understand that this

hospital no longer exists, and was replaced by the Royal Bournemouth Hospital. As a result of the transfusion Jane was infected with HCV. My wife died from liver failure on 13th November 2015, aged 54 years old.

- 5. I have spoken to Jane's mother who has confirmed that no suggestion was provided to Jane or her family at the time of the transfusion that there were any risks associated with having a transfusion.
- I met Jane about one year after her transfusion, in 1979. We were married on 14 February 1984.
- 7. In October 2004 Jane went to see her GP, Dr Nigel Cowley, because she had a very sore throat and was finding it difficult to swallow. She was given blood tests for many different things, as it was unclear what was causing her symptoms. After the test, Dr Cowley sent her a letter confirming that she had tested positive for HCV (WITN2819003). Jane was then referred to Poole Hospital for further tests.
- 8. At Poole Hospital, Jane was seen in a clinic which catered mainly to people who had contracted HCV through drug use or sexual transmission, which unnerved her. She also did not feel respected by the medical team there. When she told the nurse in the waiting room that she had HCV, the nurse visibly shrank away from her and scurried away to another room for a moment. She then returned and told Jane coldly that Jane would have to wait until the end of the day to be seen due to the risk of her infecting other patients. I felt that Jane was being treated as if she were a leper, and that the hospital didn't want to involve themselves with touching her.
- 9. We were then seen by a consultant at Royal Bournemouth Hospital, Dr P J Winwood. He told me that I would have to wear condoms during sex with Jane for the rest of my life because HCV was highly infectious. I said that I did not intend to wear condoms as this would be disrespectful to Jane and our relationship. I believe the consultant's focus on sexual

transmission was a sign of the ignorance around HCV at the time, as I later found out that transmission of HCV most commonly occurs through drug use or from contaminated blood, and transmission through sex is very rare.

- 10. Dr Winwood also told us that when Jane died, her body would need to be placed in a hermetically sealed coffin so the ground wouldn't be infectious around her. I found this to be shocking and inappropriate as we had just been informed of Jane's infection and were not given any information about her prognosis or how long she would have to live.
- 11. Royal Bournemouth Hospital confirmed Jane's diagnosis of HCV, which was genotype 1, and told her that she would need to undergo a liver biopsy. However, Jane had a serious phobia of needles and did not want to undergo a biopsy. We were told that there was a new procedure called a fibroscan, which did not involve needles and would deliver a more accurate result as the scan could get a picture of the whole liver rather than inserting a needle blindly into a section of the liver and potentially missing the most affected areas.
- 12. We were told that there were no hospitals in the UK that currently had fibroscan technology available, but that the technology was available in hospitals in Paris, Milan and Madrid. I phoned up the hospital in Paris, Bondi Hospital, and arranged an appointment, which we paid for privately.
- 13. The fibroscan in Paris confirmed that Jane had scarring on her liver. The doctor informed us that Jane would require further medical treatment and regular monitoring, but we did not want to do this in Paris as it would be time consuming and expensive.
- 14. Jane had difficulty obtaining adequate monitoring and treatment from the Royal Bournemouth. In 2006, after 16 months of not being able to get an appointment with her consultant, she wrote a letter to our MP, Tobias

Ellwood, detailing her difficulties and Mr Ellwood wrote to Dr Winwood on her behalf. Dr Winwood responded in July 2006 confirming that Jane had not been seen since February 2005 and apologising, stating 'I had written to a colleague to arrange this investigation and it would appear that this was never organised. In this respect, we are at fault and can only apologise to Mrs. Fitzgerald.' Dr Winwood went on to note difficulties in obtaining funding for HCV treatment, as follows: 'Last year, the availability of funding for the treatment of Hepatitis C was inadequate with the result that there were nearly sixty patients left at the end of the financial year who needed treatment but could not be treated within that budget. We have already committed the funds for this year and still have sixty patients waiting for treatment until the next financial year unless there is an agreement to increase funding for Hepatitis C this year.' (WITN2819004).

- 15. We then did some research into the possibility of finding a fibroscan in England, and found that the technology was available at Frenchay Hospital in Bristol. Jane asked to be transferred to Frenchay Hospital in 2008.
- 16. I do not know why we were not told about the availability of the fibroscan in Bristol earlier, by our GP or the Royal Bournemouth Hospital. There was a lack of knowledge and information at the time about HCV and I understand GPs and local hospitals may not have known about the treatments and technologies available.
- 17. We still have the same GP that we had at the time and he has been very helpful and a source of great comfort to us over the years, so I trust that he did not withhold any information from us.
- 18. We were not told by any medical professional at the time of Jane's diagnosis that Jane's HCV was caused by her transfusion in 1978. We did our own research and concluded that the only way she could have

- contracted HCV was through a blood transfusion, and she had only ever had that one transfusion in her life.
- 19. However, a note from Dr Winwood to Jane's GP on 25 November 2004 states 'Clearly the news that she has hepatitis C has come as a something of a shock to her. Disucssing risk factors with her the only one I can find is that she had a blood transfusion at the age of 16. This is the likely cause'. (WITN2819005). A letter from Jane's consultant gastroenterologist to her GP from 17 June 2009 notes 'As you know, she has chronic hepatitis C associated with a blood transfusion she received when she was a teenager. We think that she has therefore had hepatitis C for 31 years, although this was only diagnosed 5 years ago.' (WITN2819006).
- 20. I understand that in 2013, nearly ten years after Jane's diagnosis, Public Health England was notified of her infection, as there is a letter from this agency to Dr Cowley from 12 December 2013 stating that they had recently been notified of Jane's diagnosis, recommending that she be referred to a liver specialist and given treatment. This letter enclosed an information sheet entitled 'Dorset Viral Hepatitis C (HCV) Referral Pathway' which contained a flowchart of steps to take once someone is diagnosed with HCV. The flowchart did not mention infected blood as a method of transmission of the HCV virus and focused heavily on drug users. (WITN2819007.)
- 21. I believe that information about the possibility that Jane could have been infected by her transfusion should have been provided to her earlier. I understand that it was known that people had been given infected blood since the early 1990s. If Jane had been tested and informed earlier, perhaps her prognosis would have been better and she would still be alive today.
- At Royal Bournemouth Hospital, Jane was not provided with adequate information and was not treated respectfully. At Poole Hospital, she was

given inaccurate information regarding the risks of infecting others and was asked to wait until the end of the day to be seen due to her infected status.

Section 3. Other Infections

23. As far as I am aware, my wife was infected with HCV only.

Section 4. Consent

24. I believe that at the time of Jane's blood transfusion she and her mother were not provided adequate information about the risks of infection. The transfusion was not given on an emergency basis, it was given because she was anaemic, and there would have been time to fully inform Jane and her family about the risks and benefits of receiving a transfusion before administering it.

Section 5. Impact

- 25. As the HCV took effect on her liver, Jane's health slowly deteriorated and her body began to fail. She was still fairly spritely at first, as she was only in her 40s, but she had general aches and pains, became tired very easily and had trouble walking. Eventually, her body slowed down and shut down many years earlier than it should have done.
- 26. Jane suffered from the mental anguish of knowing she had a terminal illness. It weighed on her mind from the time she was diagnosed in 2004. She knew that her liver was becoming decompensated and that this would eventually kill her, but there was no way of knowing when. She did not admit it until very late in her life, but she was scared of what would happen to her. It was heartbreaking to her that she would have to leave

me, that she would never see her grandchildren grow up, go to school, or get married.

- 27. Jane developed cirrhosis of the liver as a result of her HCV.
- 28. In 2009, Jane transferred her care to Southampton General Hospital, which was about half an hour from where we lived in Bournemouth. Her consultant in Southampton, Dr James Neale, noted her past difficulties in obtaining treatment, stating in a letter on 17 June 2009, 'initially she sought care for this in Bournemouth, which is her local hospital, but unfortunately she has had problems with follow-ups, to the point where she contacted her MP to ensure that she got the care that she felt she required...she subsequently took her care to Bristol, but has also been lost to follow-up there.' (WITN2819006).
- 29. She continued to attend the clinic at Southampton for regular scans and monitoring for the next 5 or 6 years. Jane was treated by the specialist hepatology team at Southampton and we felt the standard of care was very good. Information was conveyed to us sensitively and directly in a way that made us feel better about everything. I felt the doctors were specialists in their field and knew what they were talking about.
- 30. Around 2014, Jane developed ascites which required regular draining at hospital. This started out just once a month, but eventually increased to once a week. We had to travel back and forth to Southampton for the draining, and the whole experience was extremely uncomfortable for Jane. I remember feeling terrible for her that she had to wait to be transported to hospital to get relief, and then spend hours being drained, which terrified her due to her fear of needles.
- 31. Jane was offered interferon treatment on several occasions from the time of diagnosis in 2004 until her course of treatment in 2015, but she declined to receive it because of her phobia of needles, the low success

rate for interferon treatment in people of her genotype and her knowledge of the debilitating side effects. In the meantime, her liver continued to deteriorate.

- 32. In August 2014, Jane began a 12 week course of treatment (ribavirin, sofosbuvir and ledipasvir). (WITN2819008). Jane agreed to undergo this treatment as it was interferon-free, had fewer side effects and did not involve any injections. The treatment cleared the virus, but Jane continued to deteriorate due to the advanced stage of her liver disease. (WITN2819009).
- 33. We decided to go on a family holiday to Florida in October 2014 with the two children, one daughter in law and two grandchildren. I think Jane had the sense that it would be our last family holiday before her health became too poor for her to travel. Whilst on holiday I would say things to Jane such as "we should come back here next year without the children" and she would tell me not to make plans that far in advance as she didn't know how long she would be around for.
- 34. Despite clearing the virus, Jane's liver continued to In deteriorate and it was thought she might need a liver transplant. In June 2015, Jane was referred by her doctors at Southampton General Hospital to Addenbrooke's Hospital in Cambridge for a liver transplant. In September 2015, the doctors at Addenbrooke's Hospital said that Jane's condition was showing signs of regression and that she was no longer in great need of a transplant. We returned home happy, thinking that we had turned a corner. (WITN2819010).
- 35. After this, Jane's condition deteriorated further and her body slowly shut down. She developed cancer in her lungs, and in her brain stem due to toxins from her liver. It was clear by then that her body was so weak due to her liver failure that she was unable to fight any other condition.

- 36. On 4 October 2015, Jane was admitted to Royal Bournemouth Hospital to have her ascites drained and a stent fitted in her liver.
- 37. She was in hospital on my birthday GRO-C and I remember this being the first time we had been separated on either of our birthdays ever. I visited her and told her not to worry as we would make it up when she got out of hospital.
- 38. She then returned home for a brief period, and we spent our last night together on 9 November 2015. She fell into a zombie-like stupor on the 10th November, except for a brief moment of lucidity when she pulled me out into the garden and told me that she had seen everything she needed to see and was okay now. We called an ambulance, she was brought to hospital and fell asleep. Several days later, on 13th November 2015, she was gone.
- 39. The cause of death on Jane's death certificate was initially listed as pneumonia. I was upset by this and told the hospital I would not allow Jane's body to be released for burial until the cause of death had been changed to "the administration of a contaminated blood product".
- 40. The hospital at first said they would not be able to do that, but eventually agreed to change it. Her death certificate now says that the secondary cause of death is "liver cirrhosis due to hepatitis C, acquired by transfusion of contaminated blood products" (WITN2819011). There is a note from Jane's consultant to her GP which states that "advice was sought regarding the details of part 2 of the death certificate. Given there is documentation as far back as 2004 supporting the fact that the HCV was acquired via transfusion of contaminated blood products, the Coroners office agreed it was appropriate to have this information on the death certificate" (WITN2819012).
- 41. Jane's infected status impacted on her treatment at Poole Hospital when she went there in 2004 for confirmation of her diagnosis. She was told to

wait until the end of the day to be seen. However, I don't feel that her treatment at Southampton General Hospital, Frenchay Hospital, and by her GP were impacted by her status.

- 42. As her health failed she did have to visit the dentist more regularly for dental treatment, but although she had to inform them of her infected status and they did take precautions to avoid becoming infected, they didn't make her feel uncomfortable about it.
- 43. As a result of Jane's condition, she eventually retreated from our social life. We used to go out for dinner and drinks with our friends, but our friends very quickly noticed was that Jane was no longer able to drink alcohol, and this made Jane feel uncomfortable. She eventually stopped wanting to attend. I wouldn't have left her to go on my own, so I stopped attending as well and we spent most of our time together, just the two of us.
- 44. Before Jane's diagnosis we were great travellers. We loved being active, getting exercise and our favourite place to travel was America. We used to travel to America up to twice a year, and to go on walks and go swimming in Dorset. As her condition progressed we had to reduce this to once a year because she would tire so quickly.
- 45. We have two sons and both have wives and young children. Our first grandchild was born in 2010, and Jane and I were both very excited to build a relationship with him and to make plans for the future. It was devastating for Jane to realise that she would not be alive to watch him grow up and reach milestones such as school and getting married. In the end, Jane was not even able to meet our second grandchild before she died.
- 46. Throughout Jane's illness I was unable to process what was happening as I was in denial about it. I felt impotent to help her or make her get better. I distanced myself from Jane's illness emotionally during this time

so that Jane and I could spend as much time as possible being together and enjoying her last days.

- 47. I truly felt that I could not go on living without Jane. In Jane's last lucid moment, we discussed going out in the car to our favourite place and taking our own lives together. I believe we might have done this, but were cheated of the opportunity to do so because Jane died before we were able to.
- 48. The hardest thing about seeing someone you love go through a terminal illness is not when it actually happens, because you become desensitised and numb. It's when the numbness wears off, when the desensitisation wears off, that you begin to feel the pain. That's what it has been like for me these past few years. I feel guilty because I'm still here and she's not, I can still do things and see the family grow up and she can't. I have to carry on but I don't want to, because my life is not what it used to be. One of Jane's very good friends who has supported me through this grief said to me, "your life is going to go on it has to but you have to recognise that it will never be the same again." She is right, but it has not been easy for me to come to terms with that. I can go to America and visit all of our favourite places, but it will never be the same without her.
- 49. We did feel there was a stigma around HCV when Jane was first diagnosed, in terms of the way she was treated by medical professionals, who seemed to fear they would be infected by touching her. However, we never felt that fear from anyone socially or in the family.
- 50. My children did not have the same daily contact with Jane during her illness that I did, as I was with her all the time and they only saw her when they came round to visit. However, in some ways they were more able to appreciate the impact of the illness on her as they could see how

- much she had changed each time they visited and how she was deteriorating.
- 51. Both Ronan and Ruairi are devastated that their children will not have a memory of Jane, and that Ruairi's child never had the chance to meet her at all. Mother's Day is always a constant reminder of that loss for both of them.
- 52. Before her diagnosis, Jane had worked for several different charities. She was most recently a manager at Sue Ryder, but had to quit her job in 2008 as she was too tired to do it properly and had been taking too much time off.
 - 53. I took early retirement shortly after that. I did this both to help support Jane through her illness, and because we had a conversation about her prognosis and decided that we would be happiest if I was able to spend as much time with her as possible to enjoy our final years together. I weighed up the pros and cons of leaving my work, and was offered a good retirement package, so I took it.
 - 54. Financially we were not as well off as when we were working, but we had enough money to get by. We sold our three bed house to get a two bed bungalow, and had my occupational pension from the Royal Mail. Although I would have worked much longer if Jane had not been ill, I am glad I was able to spend Jane's final years with her instead of working.
 - 55. Now that I am 65 I also have my state pension. I feel I have everything I need now, even if not everything I want. I live fairly frugally, and if I were to receive any more money I would likely give it to the children to help them out, or visit America once more to see the places that were meaningful to Jane and myself.

Section 6. Treatment/Care/Support

- 56. As far as I am aware Jane did not have difficulty obtaining any medical treatment as a result of having HCV.
- 57. Counselling was never offered to Jane or myself regarding her HCV infection.
- Jane was undergoing NHS counselling for a separate matter at the time of her diagnosis in 2004, which was set to conclude in November 2004 (WITN2819013). At that time, her counsellor asked if the sessions could be extended for a few weeks due to the impact on Jane of finding out about her infection, but this was refused by her GP.

Section 7. Financial Assistance

- 59. Jane received financial assistance from the Skipton Fund.
- 60. We were not told by any of Jane's doctors about the possibility of applying for compensation. Jane did her own research online and came across the Skipton Fund on one of the websites for people infected by contaminated blood.
- or 2005, shortly after her diagnosis. She had to get confirmation from her doctor that her HCV was caused by contaminated blood in order to make the application. She received £20,000 at this stage.
- 62. Shortly after this Jane applied for a Stage 2 payment of £25,000. To obtain this payment she had to have her doctor confirm that she had cirrhosis of the liver. She did not have any difficulties applying for compensation or receiving the funds.

- 63. In about 2006 Jane began to receive about £1,350 monthly from the Skipton Fund. These payments continued, increasing slightly with inflation, until a year after her death.
- 64. I do not receive any compensation payments myself other than a grant of £500 for heat in the winter.
- 65. I think that Jane's monthly compensation was appropriate, as it amounted to just slightly less than her salary at work. Jane loved working and would have worked much longer if she had been able to, so it was fair to pay her that amount as compensation while she was alive.
- Regarding the lump sums awarded, I am grateful for the funds we received. I know that people affected by contaminated blood in other countries, such as Scotland, did not receive lump sum payments and received higher monthly payments instead, which would have made it harder to provide for our family and retain our dignity. However, there are also countries where infected people are receiving six figure lump sums, so I am not sure how England has arrived at the figures awarded.

Section 8. Other Issues

of Jane was involved in a campaigning group for people infected by blood transfusions called Contaminated Blood Campaign. On 23 June 2011, Jane wrote a letter to her GP surgery which raised some complaints about the handling of her diagnosis. The letter asked about a) the delay in testing Jane for HCV between 1978 and 2004; b) the failure to extend her course of counselling sessions upon her request, after being diagnosed and c) the failure of the practice to distribute leaflets about Hepatitis C, which she had seen at other GP practices. In the letter, Jane asked if the practice had received a letter from 'the Chief Medical Officer, Dr Kenneth C Calman dated 3 April 1995' detailing that transfusion recipients may be at risk of contracting Hepatitis C. (WITN2819014).

- 68. The GP Practice Manager responded to her letter stating that they had not received the letter from Dr Calman, had not been informed by the blood transfusion centre that she could be at risk due to her transfusion, and that 'our knowledge of Hepatitis C has changed considerably over the last 16 years and were similar problems to occur today then I have no doubt that the systems involved in terms of screening and diagnosis would be considerably better now than they were in 1995.' They also apologised for not extending her counselling sessions and offered further counselling. (WITN2819015).
- 69. After Jane's death, I started to do some campaigning around the contaminated blood scandal. In the last few years, more and more demonstrations have been happening and media interest has been building in the issue, so I wanted to join in this work as a way of continuing to fight for Jane now that she is gone.
- 70. In 2016 I was interviewed live on the BBC at the Houses of Parliament at a rally with the Contaminated Blood Campaign group, during the first action against the government. Later on that year I travelled to Witney (David Cameron's former constituency) and campaigned there.
- 71. In November 2018, I appeared on the Victoria Bradbury show to tell Jane's story.
- 72. In terms of my expectations of the public inquiry, I would like to see the ministers responsible in those days have some form of severe reprimand. I know that Kenneth Clarke MP said in a statement at one point that people who received contaminated blood should be grateful that they were given transfusions at all because it was lifesaving treatment. I am disgusted at the lack of concern shown for the impact of this scandal on

those infected, and that politicians who were involved at the time have been able to remain in post years later without any consequences.

- 1 Would like the Inquiry to provide total recognition of the enormity of what has happened. There is widespread recognition of the thalidomide scandal in the 1950s, which affected several hundred people. This is far more widespread, and the effect of it has hurt far more people. I want the government to recognise what they have done. They acted irrationally in a moment of desperation at a time when there was a shortage of donated blood available in the UK, and gave out infected blood to patients without thinking of the consequences of not testing it. It is important to me that there is recognition of what happened and steps taken to ensure it will never happen again. I would much prefer recognition than apologies, as no kind words are ever going to bring back the people we have lost.
- 74. I am concerned that Jane's death certificate initially did not contain any mention of HCV or contaminated blood, but simply stated that she had died of pneumonia. In the end I pushed back on this and it was changed, but I appreciate that not everyone will have been able to do this and many people will have died as a direct result of this scandal without any mention or recognition of it.

Statement of Truth

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

Signed	GRO-C
Dated	12 August 2019