Witness Name: Mrs Susanne Cullen
Statement No.: WITN1858001
Exhibits: 0
Dated: 22 November 2018

WITNESS STATEMENT OF MRS SUSANNE CULLEN

INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is Susanne Cullen. My date of birth and address are known to the Inquiry.

2. I am Stephen Cullen's wife; I call him Steve, we have a son called Stephen who is 37. Steve was infected with Hep C in 1982. I tested negative in 2006, I am not sure if I was ever infected and cleared the virus myself or if I have never been infected, but I could have been very easily infected between 1982 and 2006.

Section 2: How Affected

3. My husband Steve was infected on the 14 June 1982 at Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW when he received 2 units of whole blood during a ureter lithotomy to remove a kidney stone. The surgery

was planned to be keyhole surgery. Two units of blood were ordered on 11 June 1982 for Stephen's surgery on 14th; 3 days in advance of the surgery. We have a copy of the blood transfusion request form, from that day, clearly showing the request for 2 units of whole blood. The form includes what we believe to be batch numbers, "745 860" and "745 872" that were required for the surgery. We were informed by the Skipton Fund years later that there should have been another part to the request form confirming whether the blood had been used or returned to the blood bank and as this could not be found this was initially used as a reason for us to be denied access to the Fund.

4. My husband was informed by a surgeon friend some years after his surgery and diagnosis with Hepatitis C that the operation he actually had was much bigger and more serious than the original keyhole surgery that was planned and that it could not have been performed without a blood transfusion because the tools that would have been used for the surgery meant that some blood would be lost.

5. Neither Steve nor I were informed about the risk of him being exposed to infection. He did not know and nor did I that there was even a chance that he might need a blood transfusion.

6. Following his ureter lithotomy, it took Steve 6 or 7 months to start to walk again and he has been very unwell since. I think that Steve began to develop Hepatitis C symptoms within 1 year of the blood transfusion. These symptoms included fatigue, constant weakness and coughing regularly. We did not know this at the time and have only really realised now in looking back that these symptoms were linked. Around this time, I recall that Steve was visiting the doctor on at a weekly basis. He felt like he had flu constantly.

7. Even though Steve was infected with Hepatitis C in 1982; he was not diagnosed until 2006. At that time he had been in hospital because of uncontrolled blood sugars and a chest infection. One day during a ward round a general hospital

consultant asked if he could examine Steve; he told Steve that he thought his stomach looked really enlarged, he also commented on the size of his liver and asked Steve if he was a drinker. Steve has never been a drinker or a smoker. The consultant referred Steve to a liver specialist. Following an ultrasound scan and biopsy Steve was diagnosed on 1 June 2006. The diagnosis was later confirmed in a letter dated 19 July 2006.

8. Steve was told quite coldly that I, GRO-C would have to be tested for Hepatitis C and GRO-C for HIV. This was a terrible time for us as a family, we didn't know why. We were all in shock; we didn't know what Hepatitis C was or what it meant. We had heard about HIV and couldn't believe this was happening to us. I didn't know what the risk of infection to me or my son was. This was never discussed. Steve was made to feel that he had done something terribly wrong. At the time, Aids was all over the news and so the time between the test and the results was awful.

9. We were not given adequate information to help us understand the infection and to manage it. I have slowly and sadly watched as Steve's health has deteriorated over the years. I know that his liver specialist refuses to acknowledge a link between Hepatitis C and any of his conditions including his intracranial pressure and depression which have made our experience with this even more difficult. Everything has been a fight for us. Even though Steve has "cleared" the virus, I worry now that he is not being followed up for his Hepatitis C and has been discharged from all liver care.

Section 3: Other infections

10. I believe that Steve has been infected with Hepatitis C only.

Section 4: Consent

11. I do not believe that Steve was treated or tested without his knowledge; but, I do believe that he was treated without proper consent because he was not

consulted about and did not consent to a blood transfusion even though the 2 units of blood had been ordered in advance of the surgery. He had no knowledge about the possibility of needing a blood transfusion or what it might mean to receive one including the risk that it carried.

12. I do not believe Steve was tested or treated for the purposes of research.

Section 5: Impact

13. Following the ureter operation in 1982 Steve's health deteriorated significantly.

14. Steve did suffer from kidney stones prior to the blood transfusion; however, it seemed that afterwards, their frequency increased. Steve got further kidney stones in 1986, 1988, 1994, 2001 and 2003 and numerous bouts of pneumonia requiring frequent hospital stays.

15. Steve had regular visits to his GP because he suffered daily severe fatigue and headaches so bad that they made him sick and unable to stand. His body was swollen; his feet burst through the trainers he wore.

16. In 2003 Steve had a stent fitted due to kidney failure caused by a kidney stone, the stent was only supposed to be left in for 6 weeks. As a result of cancellations to planned surgery, it was left in for 6 months. This delay caused the stent to fuse to his kidney requiring two further operations and several lithotripsy treatments to remove. Steve now has permanent damage to his kidney. The surgery itself caused irreversible damage to his urinary system including his bladder, ureter and prostate. His urinary system is now enlarged and malfunctioning; he is prone to water infections and gets these once per month.

17. Steve now has an enlarged prostrate as a result of the stent removal; this required surgery in 2004 to make it easier for him to urinate. The surgery did not take place as the anaesthetist advised him that it was too risky for him to

receive the anaesthetic. Steve was told that the condition was not life-threatening and so it was better for him to not have it. Steve has to live with the condition with the result that it takes half an hour for him to be able to go to the toilet.

18. The urology problems he suffers from include erectile dysfunction which has really affected him and which made his depression worse.

19. In April 2004 Steve visited his GP because he noticed a smudge in the vision of his right eye. He was told it was nothing to worry about, just something to be aware of for his next visit. Luckily he went to eye casualty. On the day that he visited eye casualty he was diagnosed with Idiopathic Intracranial Hypertension (IIH) and was hospitalised for two weeks for treatment. While in the hospital he had a lumbar puncture to reduce the pressure on his brain, but at this point he had already lost 50% sight in his right eye. This is the worst condition for him because of the continuing threat of blindness. He has told me that he absolutely could not live with blindness. This made me feel that we had no support at all particularly from the GP; Steven could have become blind because of his lack of care.

20. In June 2005 Steve had an optic nerve fenestration to protect the remaining sight in the right eye. This was pioneering surgery which was successful at the time, but has transpired to be only a short term solution.

21. Later in 2005, Steve was diagnosed as having type 2 diabetes and acute obstructive sleep apnoea; he uses a Continuous Positive Airways Pressure (CPAP) machine every night. This is high pressure oxygen being forced into your lungs to keep your lungs open. Steve believes that the IIH and the depression stem from the Hepatitis C.

22. In 2006 Steve was diagnosed with angina.

23. In January 2007 it was discovered that Steve had sarcoid pulmonary nodules

on his lungs, thankfully these were thought to be scarring from the numerous bouts of pneumonia he has had.

24. Steve and I believe that all of these medical conditions; apart from the kidney stones and the resulting problems associated with the surgery he had for that, have resulted from the Hepatitis C. We understand that the chance of a man developing IIH is extremely low. It has never been investigated as to why Steve had the chemical imbalance which led to the intracranial pressure but he and I are convinced the chemical imbalance was caused by the 24 years of Hepatitis C messing with the functioning of his liver.

25. Steve was diagnosed with clinical depression in around 2002; I believe he was suffering from depression for many years before his diagnosis. Steve believes that this has come about as a result of the intracranial pressure and erectile dysfunction. He believes that the depression and intracranial pressure are ultimately linked to the Hepatitis C; both have prevented him using the outdoors in the way that he used to.

26. Steve began treatment for Hepatitis C on the 27 March 2007 and had 48 weeks on Interferon and Ribavirin. Steve was not closely monitored by his GP during this time, although he did have a Hepatitis C nurse who was helpful.

27. The treatment was extremely harsh, most days he could not even sit up. His depression became much worse during the treatment period. After the first couple of months, on a daily basis he used to wish he would not wake up. He dreaded the next day coming. He had many suicidal thoughts during this time and he started to become more and more forgetful. In the July of 2007 Steve developed an ulcer the size of a 50 pence piece on his tongue and had to have surgery to remove it. He also developed ongoing problems with his joints for which he required morphine.

28. In November 2007, whilst still on treatment, he lost 30% sight in his left eye. This occurrence was extremely difficult for him. He had a further optic nerve

fenestration to save what was left of his sight. He was too ill at this time to be put under anaesthetic; his eye surgeon agreed to do the procedure whilst he was awake to save him from going blind.

29. The Hepatitis C treatment came to an end in April 2008 and by this time Steve was using a wheelchair outside of the house. After the treatment finished we expected Steve to feel much better, but he never did.

30. In January 2009 Steve was diagnosed with arthritis and in February 2010 was found to have bulging/protruding discs, a crumbling spine and osteoarthritis and we were told by the pain clinic that there was nothing more they could do for him.

31. In October 2014 Steve developed severe pancreatitis and had to have his gall bladder removed. A PET scan revealed a 15mm cystic legion on the tail of his pancreas which would have been easily removed in a healthier person, but the risks of anaesthetic to Steve meant they could only monitor the situation for him.

32. Bowel polyps were also identified around this time; Steve had 6 removed in 2015 and 4 in 2016. We understand that these carry cancer risk and Steve now must have a yearly colonoscopy.

33. Steve suffered raised intracranial pressure in March 2016 requiring a lumbar puncture. This confirmed that the optic nerve fenestrations were no longer protecting his remaining sight. In May 2017, in order to prevent him from going totally blind, Steve had to have brain surgery to fit a shunt in order to drain away excess fluid from his brain to his stomach. The surgeon agreed to perform the surgery despite the risk to his health because Steve had told him that if he lost his sight he would not want to live any more anyway. The drain into his stomach was fitted incorrectly the first time round and he had to have a further operation, one week later to correct this. Steve suffers from severe headaches most mornings; this is because the pressure builds over night while he has been lying down. He cannot function at all; he cannot stand up, cannot see and

cannot get out of bed. He takes his tablets first thing and has to wait for these to take effect so as to be able to manage getting out of bed. Some days are worse than others. As the drain works on gravity, he must always remember to slowly get to a seating position because getting up too quickly can result in the fluid draining away and him becoming very dizzy and fainting.

34. Steve has severe tinnitus which is linked to the intracranial pressure and which causes major problems in busy and crowded, noisy places, this is one of the reasons he finds it very hard to socialise. Steve's brain fog makes him very forgetful and he finds it very difficult to take in and recall information.

35. Steve takes 20 tablets a day for pain, including morphine, gabapentin and co-codamol and on average 150 units of insulin.

36. Following a really bad time with depression in 2014 (as a result of the deterioration in his health overall) and in 2017 (as a result of the serious risk of blindness to Steve, he had learned that the optic nerve fenestration operations were no longer going to offer protection to his sight) Steve's doctor referred him to the mental health crisis team for assessment. They recommended a stronger medication. The doctor also suggested counselling for psychological support, but Steve has not been able to face it.

37. Steve has testosterone injections every 6 weeks; he was found to have no testosterone in his system. These injections help with the depression but they do not help with mood swings when even the slightest problem can cause him to go into a rage. Steve's depression makes him very unreasonable and I often say that he does not realise how unreasonable he is being. The uncontrollable blood sugars and constant pain he is in also make him very difficult to be around and he can be argumentative.

38. Steve was only 27 years old when he was infected and at the time he was working as a labourer in the building trade. Due to illness he could not deal with the manual work and so in 1988 he changed his job and began working in a

fishing tackle shop. He worked his way up to manager of the shop and the fisheries at Mallory Park, Leicester. He was well respected by colleagues and customers and was often invited as a minor celebrity to hand over awards and trophies at various fishing club events. He was a successful competition angler and a clay pigeon shooter, both of which he had to give up, along with his gun licence, once diagnosed and medicated for depression. He managed to continue to work even though very ill until 2003, 3 years prior to his Hepatitis C diagnosis.

39. The financial effects of Steve being unable to work from 2003 obviously had a major effect on our finances. In the beginning I dreaded opening post and taking calls; people were constantly chasing for money and I found this very difficult. Apart from the £20,000 that we received from the Skipton fund in 2007, we had no financial help until 2012. By 2012 we were £30,000 in debt and scared. I was willing to go cap in hand and beg, to jump through hoops and plead to get any help we might be able to get. When the money finally came I was (we were) very grateful for it. Unfortunately, I do feel this is what I have been made to do, and it is something we continue to have to do. I have always had a very high, good work ethic; I had a job from when I was 12 years old. I have always been a hard working. When I have had to beg for help it has made feel bad about myself because I have not been able to provide for my family. I worked as much as I could but it was not enough for what we were faced with.

40. I feel that I have gone without, and despite having worked really hard I have never been able to buy something full price. I have always only been able to search in the reduced sections and have only ever bought what was needed. I have never been able to buy something just because I liked it. I have made excuses not to go to the Christmas party as I could never afford to buy an outfit. I remember colleagues looking forward to their pay day. I have never felt that I have had a pay day; to me I have just had more time to pay the bills again and to be worried that there would be nothing left, especially if there was an emergency. I recall listening to my colleagues chatting about what they were

going to treat themselves to; they would be buying new clothes and going out or visiting the hairdressers. I haven't been to a hairdresser for 20 years; I just have a friend come to the house and cut it. These things are very trivial especially when you are dealing with life and death and I have never really minded, but, these small things build up your self-worth and well-being and to always have to put your needs behind others has a detrimental effect on your self-esteem.

41. Our son Stephen is 37 years old, GRO-C.

GRO-C

42. Although affected and not infected the impact on my life has been severe. I have watched my husband go from a fun-loving, life and soul of the party-type, a leader, to a shell of the man he once was. I have watched him with such pride deal with pain and suffering that few people could even bare.

43. I have been afraid to come home at times. I have been so worried that on his darkest days, he may have even taken his own life.

44. When our son was born in 1981 GRO-C, he could not have been a better and prouder dad. He was involved in every aspect of Stephen's life; we were a team, always the three of us together GRO-C GRO-C. People quickly realised it was all three of us or none of us. Gradually over time, after Steve was no longer able to work, fair-weather friends disappeared, not able to deal with the restrictions of his health; not understanding of the depression and outbursts.

45. My career has also been affected, my work has always been very supportive to us as a family, understanding the situation we were in and allowing me to come and go as needed, to work from home when necessary and to make up time at 5am when the family was still asleep, which my work ethic insisted on. My managers' and colleagues' only complaint was that I didn't allow them to help more. I was always very grateful for all the support.

46. I only planned to have a year off work to help Steve recover from his brain operation in 2017 but I have not been able to return to work myself yet and although I would love to, I still cannot see a future time when this will be possible. My work is keen for me to return and has offered other jobs since but I have been unable to return. I really miss my career.

47. Due to my commitments at home, I missed out on travel with my job. As I worked for an American company, there was great opportunity to travel and network with a view to moving to the USA, which had been a dream of mine since a young girl. This would just not have been possible with Steve's health and I would not have been able to support both him and our son on my own.

48. We did have a very strong marriage; we have been together for 38 years, married for 35 and never really had cross words. The fact we were so close has helped immensely with all the stress, I was always by his side, supporting him. When he was diagnosed I was so worried about everything but especially about what would happen to our son if we were both infected. I was in shock and so grateful my test came back negative. I felt strong, I just wanted Steve to survive the treatment and I was prepared to do whatever I had to do to keep a roof over our heads.

49. Steve's mental health has taken its toll on our relationship particularly over the last few years; his depression and the prescription drugs mean he has many angry outbursts, they are not violent outbursts but he can be very mean and hurtful. He has 6 weekly testosterone injections which help his depression, but this coupled with the uncontrollable blood sugars cause him to be angry, be

argumentative and difficult to deal with. Sometimes these outbursts can be caused by such trivial things like giving him the wrong spoon or can be over something that I have absolutely no control over, like being in a queue too long whilst he was waiting for me. I feel that I am forever treading on egg shells, trying to pre-empt every little problem before it happens. I find this stressful and exhausting and although I try to forgive him every day, this has taken its toll on our relationship and my own mental health too.

50. Steve's outbursts mean that we have very few close friends, fair-weather friends disappeared long ago and my family either live far away or have their own problems. My mum now in her 80's has always been a great help and support, especially with my son. She has recently moved in with my sister who lives a 3-hour journey away and I am positive she did this, so that she would not become a further problem for me in her old age. But I miss her and her support every single day.

51. My physical health has also been affected, through heavy lifting in helping Steve in and out of the bath, pushing his manual wheelchair. We now have an electric wheelchair, which has absolutely changed our lives. I have had an operation on my right arm and both hands. I had to have the surgery on the right arm because of trauma caused by heavy lifting. I can no longer straighten my arm and have no strength in it. I am in constant pain and it can often give way unexpectedly, even holding just a cup of tea. The stress of working full time and the work load at home looking after GRO-C caused my hair to fall out and for me to have a stressed bladder, which means I want to go to the toilet all the time. The only medical solution is to have an injection in my bladder which would stop the urge all the time, but my bladder would burst if I forgot to go. These are very trivial medical problems compared to Steve's, but are still relevant.

Section 6: Treatment/Care/Support

52. It took 24 years for Steve to be diagnosed with Hepatitis C. Once diagnosed, it

took 2 years for him to get treatment and clear the virus. I am not aware of other treatment that he could have had. Overall, he did not have any trouble getting the treatment he needed. I do fear for the lack of follow up that we now face; he has not had any follow up since he cleared the virus in 2008.

53. Steve has been made to feel dirty and unclean over the years especially when blood has been taken at the hospital because he has been segregated, he has also been placed into isolation during hospital stays and has been told that he will be last in theatre as it has to be specially cleaned after him.

54. I have seen Steve suffer from a lack of proper support from his GPs over the years. Everything is a fight with them. A lack of continuity of service does not help. Steve (we) desperately need continuity of care so that he can be cared for properly. The GPs he sees look at their tiny little bit and not at the overall picture for him and his health. Steve seems to be fobbed off constantly and as a result of years of this, he tends to avoid going to the GP. It is my belief that there should be a GP dedicated to deal with all of the medical conditions that Steve is dealing with. I feel that no-one has taken ownership of his condition(s) so that he can receive the proper care he needs now and in the future. My expectation is that his condition will just get worse and worse.

Section 7: Financial Assistance

55. We were told about the Skipton Fund by Steve's Hepatitis C nurse; Jane Laurentti. Jane is the one person that helped us so much. The Skipton Fund told us about the Caxton Foundation.

56. We experienced great difficulty in accessing the Skipton Fund initially and at the time this was the only Fund that was available to help. Although Steve had been diagnosed with Hepatitis C in June 2006, we did not receive a payment until September 2007, despite making the application straight away. It has been through real persistence and finding a person who wanted to help at the other end, that we managed to get some help.

57. I have taken care of all of the forms and paperwork to help us gain access to the Funds.

58. From 2007 to 2012 we received no financial support at all. Steve had not worked since 2003, and I was doing my best to support us. By the time we had the next available help from the Caxton Foundation in 2012, we were £30,000 in debt and in desperate need of any help.

59. Despite the difficulties we have encountered, we have really appreciated the help we have received, especially in May 2017 when Steve was in Queens Medical Centre when the Caxton Foundation stepped in to help and seemed to understand the desperate situation that we were in. They supported us through the day to day demands of the situation we were in. Queens Medical Centre is located quite a distance from our home. I couldn't drive, there was no parking and someone needed to be home for our son. Steve also needed me. Caxton helped me by dealing with my emergency needs over the telephone; they placed money in my account to help with things like taxi's and hotel accommodation for my family. They also allowed me to deal with the paperwork they needed after I returned home from hospital; this gave me and my family some necessary breathing space.

60. The Funds usually work through application, and believe that if you can access money up-front by borrowing it or through other means then you don't need to apply for their support. This attitude has traditionally been very difficult to work with.

61. I have felt that I have had to beg for help, I have had to jump through hoops to get help. I (we) have had no choice. Recently I had to call EIBSS as we had no hot water or heating and desperately needed help with emergency repairs. I was advised to get two quotes (incurring two call-out charges) and to not get the repairs done pending approval. In the end we had to wait 7 days before we knew we could have the support we needed and we only got this as I emailed

our MP and complained to the Inquiry team. EIBSS has not been set up to work with emergencies that come up; the Fund expects you to wait, and sometimes months to receive an answer from them even to an urgent request. I very much feel that common sense is not always present in their decision making. I believe there should be an emergency pot of money available through EIBSS in the same way as there is through the Caxton Fund. Something should be available for emergency situations.

62. Please see below the help that we as a family have received and that we are so grateful for. Please note that the figures are approximate:

- February 2012 - £3,450 for a replacement boiler, £520 for a replacement fuse board, £4,000 to pay balance on a car loan, £2,800 towards adapting the bathroom;
- May 2012 - £3,414.88 for pay debts;
- June 2012 - £1,450 to replace flat roof on garage;
- July 2012 - £700 towards a replacement washing machine, fridge freezer and tumble dryer;
- August 2012 - £250 towards a new hoover, £485.46 to cover laminated flooring;
- December 2012 - £5,000 towards replacement front door and replacement conservatory roof;
- April 2013 - £300 towards a washing machine;
- April 2014 - £500 towards car repairs;
- July 2014 - £5,000 replacement drive to help with wheelchair access;
- November 2014 - £5,000 towards clearing debt after dealing with pennywise;
- April 2015 - £325.00 car repairs, £250 clothing allowance for wife, £500 clothing allowance for me;
- March 2015 - £150 car insurance access, £96.90 burst car tyre
- July 2015 - £2,000 respite break
- March 2016 - £255 house repairs: emergency electrician and plumber;

- June 2016 - £250 clothing allowance, £3,700 mobility scooter, £710 towards new bed;
- August 2016 - £1,033.50, trailer for mobility scooter;
- January 2017 to March 2018 - £250 monthly income top up;
- May 2017 - £1,015 payment for hotel stay and taxi's while I was in Queens Medical centre having brain surgery, £500 clothing allowance;
- July 2017 - £1,400 Motability car deposit;
- August 2017 - £720 taxi costs Queen's Medical Centre;
- March 2018 - £999 dental treatment;
- April 2018 - £2,473.41 electric wheelchair;
- May 2018 - £1,500 respite break.
- September 2007 - £20,000 received from Skipton Fund;
- April 2016 to March 2017 Skipton Stage 1 payments - £250.00 per month = £3,000 in total annualised;
- December 2016 - £500 lump sum annual winter fuel allowance;
- April 2017 to March 2018 Skipton Stage 1 payments - £252.50 per month = £3,030 in total;
- December 2017 - £500 lump sum annual winter fuel allowance.
- April 2018 – One month payment of £1,250;
- May 2018 to date - £1,500 monthly payment (SCM);
- April 2018 to date - £479 monthly payment for income top up;
- December 2018 - £500 lump sum annual winter fuel allowance due.

Section 8: Other Issues

63. I feel that all blood transfusion patients should have been screened for Hep C and HIV when a risk was first realised. At the time the virus had been discovered it had been in Steve's body for 24 years and had already done irreversible damage. Information should have been provided to him earlier, the blood units for his ureter operation were known, and could possibly have been checked so that we could have found out about the possibility of him having been infected. The deterioration in his health and in the quality of our life might

have been prevented.

64. I want the Inquiry to make sure that no one is above reproach in this search for the truth; I want it to apportion blame to those responsible and to use the full force of the law to prosecute any wrong doing.

65. I want financial support for my family going forwards and compensation for the loss of a full and active life, for the loss of a successful career and for the never-ending pain and suffering. I also want recompense for monetary losses such as salary and pension. I would also like to have counselling/ therapy for me.

66. I would also like the Inquiry to focus on the lack of support that we have experienced from our GPs over the years and to consider whether it might be possible for there to be a support provision somewhere that looks at my husband's condition in a more holistic way.

Statement of Truth

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

Signed: GRO-C:Cullen

Date: 22/11/2018.