Witness Name: Mr Stephen Cullen
Statement No.: WITN1859001
Exhibits: 0
Dated: 22 November 2018

WITNESS STATEMENT OF MR STEPHEN CULLEN
INFECTED BLOOD INQUIRY

Section 1: Introduction

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

2. I live at home with my wife Susanne of nearly 35 years and my son, Stephen GRO-C. I no longer work and my wife has given up her career to be a full-time carer to myself and our son.

Section 2: How Infected

3. I had been suffering with kidney stones since I was a teenager. These tended to pass in time; however, I experienced difficulty with one particular stone which had become stuck in the ureter and which caused considerable pain. This led to the requirement for surgery which was planned to be keyhole and through my left side. During the pre-operative appointment (approximately one week prior

to the surgery) the surgeon explained to me that he was going to make a one inch cut in my side, take the ureter out, remove the stone, put the ureter back in and stitch the incision. He made a felt tip pen mark on my side at the pre-operative appointment to show me where he planned to operate and the size of the incision he intended to make.

4. On the 13 June 1982, I attended Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW for the surgery on the 24, the next day, as planned. I signed a general consent form on 13 June 1982. I was not ever informed about the requirement for or risk of infection from a blood transfusion if I had one.

5. I can see from my records that blood for my surgery was requested on the 11 June 1982 (3 days in advance of it). I am not sure why this was the case because I was only supposed to be having keyhole surgery. I have a copy of the blood transfusion request form from that day, clearly showing the requirement for 2 units of "O Negative" whole blood. There are numbers indicated on the request form which are: "745 860" and "745 872". The form also shows that these units were required for my ureter lithotomy surgery on 14 June 1982. I understand from the Skipton Fund that there should have been a part of the form confirming if the blood had been used or returned to the blood bank and as this could not be found, this was used initially as reason to deny me access to the fund; Skipton stated the form was not completed properly.

6. I was informed years later by a surgeon friend that the operation that I actually had, would not have been done without a blood transfusion because the tools that were used back then, were not cauterizing scalpels that seal the wound as it is cut and which help to reduce the amount of blood lost. I understand that there would not have been a vast amount but that there would have been some blood loss, which makes sense as it seems I was transfused with 2 units.

7. The surgery took place on the 14 June 1982 as planned. When I woke up I was in severe and unexpected pain. I realised at I was on oxygen and that a wound drain, catheter and a drip had been inserted. I noticed that I was being given

heroin as pain relief. I asked the nurse why I felt so much pain; I couldn't understand why I was waking up like this, I expected to waken up as if I had a tooth taken out. The nurse explained that when they went to the left side to remove the stone, the surgeon couldn't find it so the surgery actually involved opening me up extensively to remove my bowel and intestine to find the stone. I was cut from my left side to my right groin. They found the stone.

8. It took me 6 or 7 months from my surgery to start to walk again and I have been very unwell since. I had symptoms within 1 year of the blood transfusion including fatigue, constant weakness and coughing regularly. For example, around this time, I recall being invited to a special invitation only pigeon shoot. I went because those invitations did not come often. I remember not being able to walk alongside the 80 year old gentlemen that were there. In the end I sat on the buggy that accompanied us around the course. At the time, I could not understand this. At this time, I was going to the doctor on a weekly basis. It felt like I had flu constantly. I was drained.

9. I have been infected with Hepatitis C and I believe that I was infected from the blood that was transfused to me during the ureter lithotomy in 1982. My journey to this discovery was a long one; it took until 2006 for me to be diagnosed with Hepatitis C. During a hospital stay for uncontrolled blood sugars and a chest infection in January 2006, a general hospital consultant doing ward rounds with student doctors asked if he could examine me. My stomach was particularly enlarged at this point and he commented on the size of my liver and asked if I was a drinker. I advised I had never been a drinker or a smoker, he asked if he could refer me for tests on my liver. This general doctor referred me to liver specialist and it was this liver specialist that uncovered through an ultrasound of the liver that I had hepatomegaly. I have medical records that show this. The specialist noted that my blood tests gave a raised ALT of 646, that I did not drink alcohol and did not have any other risk factors. He also noted that my ALT Levels had been raised since 2003. I was unaware that my ALT Levels were raised and what that might mean. I had a liver biopsy and was diagnosed

with Hepatitis C on 1 June 2006; this was confirmed in a letter dated 19 July 2006. At this point my ALT Levels had increased to 1300 which I understand is very high.

10. When I was told that I had Hepatitis C I was told I had Geno type 1a and very little other information, they (the medical profession) had not asked if I had ever had a blood transfusion and nor did they mention the risk involved with that. They mentioned it may have been from my tattoos, but, I got those in 1970 and didn't have any sickness from then until 1982.

11. I was also told quite coldly that my wife and son would have to be tested for Hepatitis C GRO-C. This was a terrible time for us as a family, we didn't know why. I didn't know what the risk of infection to my wife and son was. This was never discussed. We didn't even know what Hepatitis C was or what it meant. I was made to feel that I had done something terribly wrong. At the time, Aids was all over the news GRO-C GRO-C. I felt at the time that Hepatitis C was a better outcome than HIV.

12. I was not given adequate information to help me understand and manage. In the years since my liver specialist has flatly refused to acknowledge that there is any link between Hepatitis C and any of my conditions including the intracranial pressure and the depression. I fear now for the fact that I have been discharged from all liver care because I have been deemed to have cleared the virus. I am not sure whether this is the standard of care across the NHS at present.

Section 3: Other infections

13. I believe I have been infected with Hepatitis C only; however, I have no confidence that I do not carry another virus.

Section 4: Consent

14. I do not believe that I have been treated or tested without my knowledge; but, I do believe that I have been treated without proper consent because I did not agree to the major ureter operation that I had in 1982 and I was not consulted about and nor did I consent to a blood transfusion.

15. I believe I have been treated without adequate or full information because I was never told that I might need a blood transfusion even though blood units were ordered in advance of the ureter operation and I was never consulted in relation to this. I had no knowledge of what it might mean or the risk that it carried.

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

Section 5: Impact

17. Following the ureter operation in 1982 my health deteriorated significantly.

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

19. Aside from this I had regular visits to my GP because I had daily severe fatigue and headaches so bad that they made me sick and unable to stand. My body was swollen, my feet burst through trainers I wore, just from standing.

20. In 2003 I had a stent fitted due to kidney failure caused by a kidney stone, but because of cancellations the stent was left in for 6 months rather than 6 weeks maximum. This delay caused the stent to fuse to my kidney which required two further operations and several lithotripsy treatments to remove. I now have permanent damage to my kidney. The surgery also damaged my urinary system including my bladder, ureter and prostate. My urinary system is now

enlarged and malfunctioning. I am prone to water infections; I get these once per month. This causes problems with blood sugars.

21. The urology problems that I suffer as a result include erectile dysfunction which has really affected me and has made my depression worse. A camera in my bladder showed sludge, like frogspawn, to the specialist who had not seen anything like this before. This was flushed out. I mention this because I feel it may be connected to the Hepatitis C.

22. I have an enlarged prostrate as a result of the stent removal; I required surgery in 2004 to make it easier for me to urinate. In the end, the surgery did not take place as the anaesthetist advised me that it was too much of a risk for me to have the anaesthetic. He told me that the condition was not life-threatening and so it was better for me to not have it. The result is that I have to live with the condition with the result that it takes half an hour for me to be able to go to the toilet.

23. In April 2004 I visited my GP doctor because I had noticed a smudge in the vision of my right eye; it was like a white blurry, ghost image at the side of my vision. My GP advised me just to mention it to my high street optician when I was next there. I was told it was nothing to worry about, just something to be aware of for my next visit. I was unhappy with this so I took myself off to eye casualty. The day that I visited eye casualty I was diagnosed with Idiopathic Intracranial Hypertension (IIH) and I was hospitalised for two weeks for treatment. IIH is a build-up of pressure on the brain. While I was in the hospital I had a lumbar puncture to reduce the pressure, but at this stage I had already lost 50% sight in the right eye; I have no lower vision from half way down this eye. This is the worst condition for me. It is the worst because of the continuing threat of blindness. If my legs or arms were cut off I could deal with that, but going blind, I absolutely could not deal with. This condition is trying to take my sight from me, all of the time. It is because of this condition that I have been unable to work. My neurologist told me in 2007 I would never be well enough again to go back to work, although I have not worked since 2003.

24. In June 2005 I 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.

25. Later in 2005, I was diagnosed as having type 2 diabetes and acute obstructive sleep apnoea and still must use a Continuous Positive Airways Pressure (CPAP) machine every night. This is high pressure oxygen being forced into your lungs to keep your lungs open. It's like having a Dyson vacuum cleaner forcing air down your throat. I consider that these two conditions stem from the Hepatitis C having caused me to have a sedentary lifestyle. The fatigue that I have felt over the years has prevented me from participating in the lifestyle that I once enjoyed.

26. In 2006 I was also diagnosed with angina.

27. In January 2007 it was discovered that I had sarcoid pulmonary nodules on my lungs, but thankfully these were thought to be scarring from the numerous bouts of pneumonia that I have had.

28. I believe that all of these medical conditions; apart from the kidney stones and the resulting problems associated with the treatment for that, have resulted from the Hepatitis C. I understand from some studies that only 1 in 100,000 people get idiopathic intracranial hypertension and only 2% of those who do get it are men. Usually it is overweight women of childbearing age, because it is usually caused by a hormonal imbalance. It has never been investigated as to why I had the chemical imbalance which led to the intracranial pressure. I am convinced that the chemical imbalance was caused by the 20 odd years of the Hepatitis C messing up the proper functioning of my liver. When they did the test for the liver they said that my ALT levels had been significantly raised since 2003 but no-one did anything about it.

29. I was diagnosed with clinical depression in and around 2002, I had been suffering with depression for many years prior to this. I believe that the depression has come about as a result of the intracranial pressure and erectile dysfunction. I believe that the depression and intracranial pressure are ultimately linked to the Hepatitis C. Both prevent me from using the outdoors in the way that I used to.

30. I used to shoot pigeons alone in the fields quite regularly, up to a couple of times per week. On one particular day in around autumn or winter 2002 when I went out, I recall there were no pigeons. I recall sitting with the gun barrel under my chin and reaching down to pull the trigger. I realised there was a public footpath close by and I wondered who would find me, whether it would be passing children or the farmer. I knew that if I did it there and then Susanne or Stephen would not find me because they would not know where I was. All of a sudden, I asked myself why I was doing this. The fact that I came so close worries me still; I know how close I was to doing it without even knowing why at the time. As soon as I went to see the doctor and I was diagnosed with depression, I sold my gun and gave up my licence because I knew could not trust myself again. This was a terribly confusing time in my life because I could not attribute my feelings to any one thing. I had no money or marital problems or anything else that could explain the reason I felt this way.

31. I started treatment for Hepatitis C on the 27th March 2007 and I had 48 weeks on Interferon and Ribavirin. Treatment consisted of a tablet and an injection. I attended hospital for one month's supply. I administered both the tablets and the injections myself at home. I was not closely monitored by my GP although I did have a Hepatitis C nurse who was helpful. The treatments available were on a chart and depended on the genotype that you had. The doctors didn't expect people to be able to finish the course (which was almost 12 months for me). They expected people would only last for 6 months because it was thought that the chemo would kill them.

32. The treatment was extremely harsh, most days I could not even sit up. My depression became much worse during the treatment period. After the first couple of months, on a daily basis I used to wish I could just not wake up. I dreaded the next day coming. I had many suicidal thoughts during this time. I also realised I was becoming more and more forgetful; I forgot my family's names, my sister's children's names. In July 2007 I developed an ulcer the size of a 50 pence piece on my tongue and I had to have surgery to remove it. I also developed ongoing problems with my joints for which I require morphine.

33. In November 2007, whilst still on treatment, I lost 30% sight in my left eye. I had a further optic nerve fenestration to save what was left of my sight. I was far too ill at this time to be put under anaesthetic; my eye surgeon agreed to do the procedure whilst I was awake, this was the first time this was ever done and the only way to save me from going blind.

34. The treatment came to an end in April 2008 and by this time I was in a wheelchair outside of the house. After the treatment finished I expected to feel much better, but I never did. I am not sure how I got through this; I just forced myself to take one step after the other.

35. In Jan 2009 I was diagnosed with arthritis and in February 2010 was found to have bulging/protruding discs, a crumbling spine and osteoarthritis and I was told by the pain clinic that there was nothing they could do for me.

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

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

38. I suffered raised intracranial pressure in March 2016 requiring a lumbar puncture. This confirmed that the optic nerve fenestrations were no longer protecting my remaining sight. In May 2017, in order to prevent me from going totally blind, I had to have brain surgery to fit a shunt in order to drain away excess fluid from my brain to my stomach. The surgeon agreed to perform the surgery despite the risk to my health because I had indicated to him that if I lost my sight I would not want to live any more anyway. The drain into my stomach was fitted incorrectly the first time around and I had to have a further operation, one week later to correct this. I still have severe headaches in the morning. As the drain works on gravity, I must slowly get to a seating position as getting up too quickly can result in the fluid draining away and me becoming dizzy and fainting.

39. I have severe tinnitus which is linked to the intracranial pressure and which causes major problems in busy and crowded, noisy places and this is one of the reasons I find it very hard to socialise. My brain fog makes me very forgetful and I find it very difficult to take in and recall information.

40. I take 20 tablets a day for pain, including morphine, gabapentin and co-codamol and on average 150 units of insulin.

41. Following a really bad time with depression in 2014 (as a result of the deterioration in my condition overall) and in 2017 (as a result of the further loss of sight and the serious risk of blindness to me. I had learned that the optic nerve fenestration operations were no longer going to offer me protection) my doctor referred me to the mental health crisis team, for assessment, they recommended a stronger medication. The doctor also suggested counselling for psychological support, but I could not face it at the time and I have not been able to face it since.

42. I have to have testosterone injections every 6 weeks as I was found to have none in my system. These injections also help with the depression but they do not help with my mood swings and even the slightest problem can cause me to

go into a rage. My depression makes me very unreasonable and my wife often says that I don't even seem to realise how unreasonable I am being. Uncontrollable blood sugars and constant pain can also make me very difficult to be around and I can be argumentative.

43. I have had to have dental treatment and all blood tests at hospital. All paperwork for these procedures has said "high risk" which made me feel terrible.

44. I think that the reason why I am still here today is because I am a strong and resilient person. I had a very difficult abusive upbringing which I believe made me develop an acute coping mechanism which must have helped me through this.

45. I was only 27 years old when I was infected and at the time was working as a labourer in the building trade. Due to illness I could not deal with the manual work and so in 1988 I changed my job and began working in a fishing tackle shop. I worked my way up to manager of the shop and the fisheries at Mallory Park, Leicester. I was well respected by my colleagues and my customers and was often invited as a minor celebrity to hand over awards and trophies at various fishing club events. I was a successful competition angler and a clay pigeon shooter, both of which I had to give up, along with my gun licence, once diagnosed and medicated for depression. I managed to continue to work even though very ill until 2003. I really miss my career.

46. The loss of my salary had a major effect on mine and my family's lives. We were constantly chased for money, and I remember my wife sobbing when she became too scared to open the post and answer the phone. We were lucky that she was able to work full time and had a good job, but it was not enough. Her work tried to support us in any way possible and she was allowed to come home if needed and to work from home if necessary. She was allowed to make up her lost hours at 5am in the morning, when the family was still asleep. If her

work had not been as understanding she would have had to give up work much sooner.

47. In December 2016 my wife was made redundant. I was due to have brain surgery in early 2017 and the rehabilitation required that she was at home with me for a year whilst I recovered and although her work was keen for her to return and has offered other jobs since she has been unable to return. I know she misses her career.

48. Our son is 37 years old, GRO-C

GRO-C

49. Susanne and I made the decision to keep testing for HIV quiet, at the time there was a lot of negative stigma attached. At the time, we did not think Hepatitis C was as bad as HIV and we felt able to tell others about it. I do not worry too much about what others think because this situation has not been self-inflicted. I have tried carefully to educate my family in relation to it. I am very thankful that all of my family have been supportive.

Section 6: Treatment/Care/Support

50. It took 24 years for me to be diagnosed with Hepatitis C. Once diagnosed, it took 2 years for me to get treatment and clear the virus. I am not aware of other treatment that I could have had. Overall, I did not have any trouble getting the treatment I needed. I do fear for the lack of follow up that I now face; I have not had any follow up since I was cleared.

51. I feel I have been made to feel dirty and unclean over the years when blood has been taken at the hospital because I have been segregated and placed into isolation during hospital stays and I have been told that I will be last in theatre as it has to be specially cleaned after me.

52. I also feel generally that I have had a lack of support from GPs. Everything is a fight with them. A lack of continuity of service does not help. I desperately need continuity of care so that I can be cared for properly. The GPs I see look at their tiny little bit and not at the overall picture for me and my health. I seem to be fobbed off constantly and as a result of years of this attitude, I tend to not go to the GP.

Section 7: Financial Assistance

53. I think I was told about the Skipton Fund by my Hepatitis C nurse, Jane Laurentti. Jane is the one person that helped me and my family so much. The Skipton Fund told me about the Caxton Foundation.

54. I experienced great difficulty in accessing the Skipton Fund initially and at the time this was the only Fund that was available to help. Although I had been diagnosed with Hepatitis C in June 2006, I did not receive my first 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 my wife and I managed to get some help.

55. I would not have been able myself to complete forms and get paperwork together for them, this is something that my wife has taken care of for me.

56. From 2006 to 2012 I received no financial support. Having not worked since 2003, by the time we had the next available help which was from The Caxton Foundation in 2012, we were £30,000 in debt and desperate for any help.

57. Despite the difficulties we have encountered, we have really appreciated the

help we have received, especially in May 2017 when I was in Queens Medical Centre; The Caxton Foundation stepped in to help and seemed to understand the desperate situation that my family and I were in. They really helped support me through the day to day demands of the situation I was in. They helped me by dealing with my emergency needs over the telephone, placed money in my account to help with things like taxi's and hotel accommodation for my family. This allowed my wife to deal with the paperwork after I returned home from hospital; it gave me and my family some breathing space. The Funds usually work through application, the Funds 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.

58. I have felt that we have had to beg for help and thankfully my wife has been prepared to jump through hoops to get what we could. We have had no choice. An example of this is when my wife very recently called EIBSS as we had no hot water or heating and we 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 my family and I had to wait 7 days before we knew we could have the support we needed and we only got this as my wife 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 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 this type of emergency situation.

59. Please see below the help that I (we as a family) have received and that and I am (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

60. 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 my body for 24 years and had already done irreversible damage. Information should have been provided to me earlier, the blood units for my ureter operation were known, and could that not have been checked so that I could have found out about the possibility of me having been infected? The deterioration in my health might have been prevented.

61. 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.

62. I want financial support going forwards, for myself and my family 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.

63. I would also like the Inquiry to focus on the lack of support that I 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 and treats my 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