Witness Name: GRO-B
Statement No: WITN1129001
Exhibits: WITN1129002-003
Dated: MARCH 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B 1974 and I live at GRO-B Liverpool GRO-B

2. My former partner/fiancée, GRO-B: P (born on GRO-B 1965), was infected with the Hepatitis C Virus (Hep C) from contaminated blood products. He died on GRO-B 2007 at aged 42. His Death Certificate records intracerebral hemorrhage as the primary cause of P 's death. Cirhossis and Heptatis C are recorded as secondary causes.

3. This witness statement has been prepared without the benefit of access to P s full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. P had mild/moderate Haemophilia A (8%). He was treated at the Liverpool Haemophilia Centre at the Royal Liverpool Hospital (Roald Dahl Centre) under the care of Dr McVerry and Dr Mackie initially and then Dr Toh and Dr Vanessa Martlew.

5. P and I became a couple in April 1993 when he was 27 years old and I was 19; and, at that time, P was working as a Sales Office Manager and I was working as an Administrator. P was tall, dark, very good looking, kind, generous, trust worthy and incredibly fun loving. He was everything I could have hoped for in a man and more. Together we were deliriously happy and it was clear, even within the first few weeks of meeting, that we were serious about each other. My family and friends adored P and he fitted seamlessly into my life. We started to make plans for our future together and we were so excited about what the future would hold for us.

6. We were on holiday in Greece 18 months after getting together and it was there that P proposed to me. On our return we moved in together and held an engagement party on my 21st birthday. Life was so good! The following Christmas we found out that we were expecting a baby and we were overjoyed. P supported me through a difficult pregnancy and prepared a beautiful nursery in our home. When our beautiful daughter GRO-B: D arrived on GRO-B 1996, he was the proudest daddy in the world. Despite the chaos that a new-born brings to your life, we could not have been happier or more excited for the future. At the time we were blissfully unaware that, within a few short months, our lives would be ripped apart when he would take a call advising him of his Hep C diagnosis.

7. P's haemophilia was diagnosed when he was approximately 8 years old. Records suggest that his mother sustained excessive bleeding following dental treatment. No-one in his family was previously known to have haemophilia. P has a younger brother, GRO-B, who also had mild

haemophilia but who had less instances of bleeding problems GRO-B did not contract Hep C.

8. According to P s medical records he was treated with cryoprecipitate, the first recorded use of cryo being on 2/6/1980 and the last recorded use of cryo (for a dental process) being on 22/05/1981. The first record of P being treated with Factor VIII (FVIII) in his medical notes is on 20/8/1982 and all subsequent treatments for bleeds etc from this date were with FVIII.

9. There are references throughout P s medical notes and records of him being infected with Hep C through his FVIII treatment. I refer to **Exhibit WITN1129002** (letter dated 20/7/2001) being one such example. I also refer to **Exhibit WITN1129003** being a letter from Consultant Haematologist M Mackie to P s GP dated 8/4/1986 stating that "Factor VIII is now heat treated so it certainly will be a lot safer". There are gaps within P s medical records and they are non-specific in relation to the infected batch or batches, but it is, nevertheless, logical that P was infected with HCV some time between 1982 and 1985.

10. P told me that the risk of Hepatitis C infection via FVIII treatment was *never* discussed with him. He told me that from in or around 1985 he was given heat treated FVIII and his consultants started to mention the risks of *HIV/AIDS* infection from previously non heat treated FVIII for the first time. He was clear that no warnings were given to him when being treated with Factor VIII prior to 1985. P tested HIV negative during the late 1980s.

11. P received a phone call from his regular haemophilia nurse at the Royal Liverpool Hospital during late November 1996 to advise him that he had been infected with Hepatitis C from FVIII treatment. I was with him when he took the call but there is no record of the phone call in P s medical records. P was understandably very shocked to hear this and asked the following questions:-

    1. 'How long have you known about this?' He was not given a definitive answer to this and was just told he had had it for 'some time'.

2. 'Why was I not warned about the risks?' He was told it wasn't necessarily clear to them at the time he received the treatment and, besides, if he didn't have the treatment his health could have been put at greater risk therefore he should still be grateful he was given the treatment!

3. 'Is it possible this could have been passed on to my fiancée through intercourse?' To this he was told it was 'a possibility' and that I would need to come into clinic with him to be tested.

4. 'I have a new-born baby.... If my fiancée has contracted this could the baby also be infected?' To this he was just told 'that is why GRO-B needs to be tested as soon as possible'.

12. After being told this and particularly about the possibility of myself and our daughter being infected, P become very distressed and the phone conversation could not continue. It was then arranged for myself and P to visit the haemophilia clinic for me to be tested.

13. When we visited the clinic, I had the tests done and we were told when I should return etc. It struck me how 'matter of fact' their approach was. There was very little compassion shown. It was pretty much just 'it's happened – get on with it'. I can remember P saying he felt really rather let down that a treatment that was meant to help him treat his condition had infected him with Hepatitis C. I am unable to remember who gave the response (a nurse I believe) but he was told he should maybe consider himself lucky that it was "only Hep C" he was infected with as so many people were also infected with HIV/AIDS and had died as a result. This made us both feel a little ashamed and we just kind of accepted this and said okay.

14. At the time that he was told of his diagnosis and when we both attended the clinic for me to be tested, we were given very information on Hep C. We did not see a doctor that day. To be honest we didn't really understand what it was, how it would affect P s life and just how dangerous it was. P was told was that he would be scheduled for a further appointment with a consultant and things would be explained further. In retrospect, I consider the way we were treated to be completely unacceptable given the fact we had this

news just dumped on us without any real explanation and told to pretty much get on with it. We were a young couple with a new-born baby and were not offered any sort of real support or counselling. I was only 22 years old and found it all completely bewildering. Both P and I were really overwhelmed by it all.

15. I absolutely believe that P should have been told about this diagnosis as soon as they were aware of it. Although P's records are non specific as to the date of infection etc, I have seen on P's medical records that a result of blood tests on 4/2/1988 was circled 'YES' for both Viral Hepatitis and History of Viral Hepatitis. To me this likely indicates they knew about it 8/9 years or maybe more before informing him. This is something that I find extremely distressing to this day.

16. We were told that it was unclear whether Hep C was contractable through sexual intercourse but although they considered it unlikely, we could only be sure I would be protected from infection via this route by using condoms.

Section 3. Other Infections

17. P's medical records regularly state possible exposure to vCJD. In several places vCJD is named as one of his illnesses and this makes me believe that it was their opinion that he had vCJD. I found a copy of a 'post it' note in P's records that states P received '85m (FHM 4183 1993). This is implicated batch however according to new list for HPA - this batch is low risk and doesn't require us to let pt know". This note was neither signed nor dated.

18. I have found a letter dated February 2001 amongst John's medical notes from Consultant Haematologist C H Toh advising some batches of FVIII (Replanate) was found to be from a donor who has now been identified as having vCJD. He was told that he P would have been informed if he was given this batch.

19. On 21/09/2004 P signed a form to confirming that he wished to be informed if he received any of the implicated batches of UK sourced plasma derived clotting agents of FVIII with vCJD.

20. A form, signed by Vanessa Martlew as assessor on 10/12/2004, was completed with 'YES' encircled at P being at risk of vCJD for public health purposes.

Section 4. Consent

21. P was tested for Hep C without his knowledge as prior to them informing him of his infection he always maintained that they had never discussed Hep C with him in any context at any stage.

22. Whilst looking through P's records, I noted that on page 1414 on an entry dated 28/06/1985 that blood was taken for 'Med Micro Trial'. It does not state anything other than this and does not state whether or not P was informed about this. It may be that he was included in a trial and/or research without his consent.

Section 5. Impact of the Infection

23. The effect P s Hepatitis C infection was completely catastrophic for him. There was not an area of his life that remained unaffected. Prior to P s diagnosis he was confident, ambitious, vivacious, happy go lucky and sociable. Even when he had problems with his haemophilia bleeds and inevitable stays in hospital he never once complained or let it hinder his life. He simply radiated positivity. The day P took the phone call telling him of his Hep C infection I saw a side of him I hadn't witnessed before. He looked like a startled rabbit that had been caught in headlights. He looked broken and terrified. His mind was tormented by the thought he may have passed the infection on to me or his baby girl. Even after I had been given the all clear although he was obviously so relieved the 'old P was still not back. He was detached and distracted. It was like his spirit had been crushed.

P became obsessed with ensuring neither me nor the baby were put at any risk of catching Hep C. By way of example, if he cut himself, he would scream at me to get away from the blood and would be completely obsessive in cleaning it up. He was also completely paranoid about passing it on to me through intercourse. As a result our sex life was considerably affected. He once confessed to me that as we'd been told to use condoms, each time he used one, it served as a reminder to him that he was infected and he said he felt dirty. No amount of reassurance from me made a difference. In his mind he was infected and he was dirty.

24. P started Interferon/Ribavirin clearing treatment around March 1997. The side effects were horrendous. He would have terrible shakes, sweats and flu like symptoms. His sleep was very disturbed, the bed clothes would be soaking wet with sweat within an hour or so of him being in bed. In order to try and help us both get some sleep we decided it would be better if I slept in the spare room. P was constantly tired, irritable and snappy and low in mood. After around 12 weeks P decided he could not continue with the treatment. The side effects were so extreme and added to the fact that we were both working and trying to manage the demands of a new baby it was just too difficult. He felt he should take a break and recommence it when life had settled a little. To be honest I think at that point neither of us were aware of the full severity of the damage the Hep C had and was causing to his body. P was reviewed in clinic on 27/10/1997 with Consultant Haematologist Vanessa Martlew and she reported that Hepatitis C was still detectable in his bloods after taking the Interferon from March until June 1997. Dr Gilmore stated that P should not recommence clearing treatment until after a further review in April 1998.

25. Although P's physical wellbeing improved a bit on stopping the Interferon his mood remained quite low. P was not giving as much to our relationship as he once had. Barriers were being put up and I felt I was losing him more and more with each passing month. Despite this he was still amazing with our daughter GRO-B. He adored her and she him. When I used to sit and watch them play together, I felt for that moment I had 'the old

P back. No matter how he was feeling he remained an amazing dad and the bond between him and GRO-B was very close. Along with becoming increasing detached from me P also lost interest in us doing anything socially. He would use the excuse of not getting a babysitter and instead he would just encourage me to go out with my friends if I wanted a night out. He also began to become isolated from friends that he had once enjoyed regular nights out with. Whenever I tried to discuss the Hep C with P he would close up, saying he didn't want to talk about it and it had took enough of his life away without wanting to discuss it. He also made me promise not to tell anyone other than my immediate family about his diagnosis. He felt embarrassed and felt dirty and felt that others would judge him.

26 P tried another course of Interferon at the start of 1999 but, again, the side effects were awful and it was too difficult for him to cope with and try and continue to carry on with day to day life and work. I think he stopped that particular course after about 6 weeks.

27. As a couple, P and I had continued to grow further and further apart. It was heart-breaking. P was a completely different person, particularly after the Interferon treatment and no matter how much I tried to rebuild things there was an invisible wall in between us that I couldn't bring down. Although he was still a kind and caring person to me I felt our relationship had become more like a friendship than a couple. We agreed that we both loved and cared deeply about each other but were no longer 'in love', We separated in January 2000, with me and GRO-B leaving the family home. P and I were both devastated but felt it was inevitable and we pledged to co-parent GRO-B and remain close friends. I had high hopes that that was how it would remain.

28. From 2000 onwards P s physical and mental health continued to deteriorate. He was still working but his sickness absences had started to increase. He also seemed increasingly distracted and could not seem to hold his concentration for long. In April 2001 he approached Dr Martlew with a view to re-commencing Interferon treatment (according to his medical records). She had concerns that he had not managed to finish earlier courses

due to severe side effects and family issues. However she said she would find out if funding would be available from the local authority for the further treatment which would cost £8,600. An application was to be made to NICE although there was mention of considerable delays. Whilst out shopping with GRO-B P collapsed and started to fit. D, just 4 years old, had to get help and P was taken to hospital where it was found that he had suffered a fractured skull.

29. The medical notes in relation to the incident on 24/03/2001 describe his Hep C as being 'chronic' and he was also found to have oesophageal varices. He had two more instances of blacking out/going unconscious and was under investigation through various departments including cardiac. Records show a report from a trans jugular liver biopsy carried out on 20/07/2001 revealed established cirrhosis due to Hep C and a marked deterioration of protein synthesis and serum albumin stating this clearly indicates hepatic dysfunction and he would expect to decompensate within the next 5-10 years. Dr Gilmore recounts instances of blacking out, the cause of which was at that stage still undiagnosed but, were thought to be potentially cardiac related. The fact that cirrhosis was now established was considered to be prohibitive in P having further Interferon treatment as the risks were likely to outweigh the benefits.

30 P was later diagnosed with epilepsy following a road traffic accident where he 'blacked out' whilst driving and hit a wall. He was no longer able to drive.

31. In 2002 P was dismissed from employment based on his continued sickness absences. Although this took the pressure off him having to try and maintain a working life, it caused severe financial difficulty and further added to his despondency with life and social isolation. His physical health was declining rapidly, and medical records show frequent admissions to hospital following fits which would often result in bleeds, in particular, trauma to the tongue which he would bite during the fits. His records also document the decline in his mental health and anti-depressants were prescribed. There was also concern about P s increased dependency on alcohol which was as a

result of his feelings of despair and social isolation. I was upset and angry to read some of the references to P 's alcohol consumption in his notes as the inference seems to be that that is to blame for P 's health issues (and fitting) instead of the fact that he was infected by FVIII with HCV.

32. For the following years his physical health continued its decline. Along with the advanced cirrhosis, he had oesophageal and stomach varices, thrombocytopenia (noted in his records in July 2002) and portal hypertension.

33. In 2004 P had many stays in hospital mainly caused by fits and a noted further decline in his mental health. During 2004/2005 he had several psychotic episodes where he was hallucinating and convinced people and medical staff where trying to harm him. He was sedated with Librium during some hospital admissions. On more than one occasion the Police were alerted from the hospital when he had left the ward out of fear of them attempting to cause him harm. During these years chaotic years there were long periods when he was not capable of seeing GRO-B or when he would not turn up for planned visits.

34. In February 2005 he was taken into hospital again and spent several weeks in intensive care due to problems with gastric varices. He then underwent a TIPPS procedure (Trans jugular Intrahepatic Portosystemic Shunt) which was followed with a stay in post-operative critical care unit.

35. Records also show he suffered a cardiac arrest sometime in 2005 following cardio arrhythmia.

36. During late 2006 I started to see a change in P. Although still suffering with low mood he seemed to be actively trying to improve his life as best as he could. He was starting to speak more positively about life, his hopes of getting back into some kind of employment, re-establishing social interaction and most importantly spending a lot more time with GRO-B. He was a lot more reliable when making plans and we started to spend more time together, the three of us as a family. This mainly continued during 2007 and he was

determined to make up for the time he had lost out on with GRO-B It was lovely to see them spending so much more time together.

37. On GRO-B 2007 P was taken back into hospital after suffering a fit and was released two days later. He was taken back to hospital on 11th September when he was found to be very ill at home. His condition began to deteriorate and by GRO-B they established he had the following:- intraventricular bleed, hepatic encephalopathy, uprising renal failure.

38. During my visit to him on GRO-B I was told that if P survived, he would be likely to need 24/7 care.

39. On GRO-B myself and P's brother were told that P was not expected to live and that they were applying a 'do not resuscitate order' to him. The consultant told me that due to his complex medical conditions and deteriorating health it was not in his best interests to revive him.

40. On GRO-B P was placed on the dying pathway. In the early hours of GRO-B P died. Brain Haemorrhage and Hepatitis C are noted on his death certificate.

41. P's diagnosis and subsequent mental and physical illness has had a major impact on my life from the moment he was diagnosed to present day. As I've explained, the changes that it made to him and how he was I feel ultimately brought irreparable problems to our relationship and as much as we still loved each other we were no longer a couple, purely two people living in the same house and co-parenting and the end of our relationship felt almost inevitable. The seven years following our split prior to his death were extremely difficult years for me as I could see his mental and physical health rapidly declining before my eyes and there seemed to be nothing that I could do to help him. It was extremely distressing for me to witness the once strong confident man reduced to a pitiful man in complete despair. He was almost unrecognisable physically and even more so mentally.

42. After one instance in 2004 when he was seriously ill and it was felt that he might die I began with a serious sleeping problem that I still have to this day. I spoke to a therapist about my insomnia last year and she explained it was brought on by that traumatic event and I still live with it now as my mind has not properly dealt with the trauma.

43. A major part of my distress from 2000 to 2007 was witnessing the effects that P s illness and decline had on our daughter GRO-B As a mother I protected her from the horror of P s infection as she was simply too young to understand. However it was impossible to hide the decline in P s physical and mental health from her and she would often ask if her dad was okay, I could see she was worried about him. Due to his declining physical health he was unable to care for GRO-B for anything more than a couple of hours and this would only be on occasions when he was fit enough. As P 's mental health declined this meant it was often inappropriate/unsafe to leave his young daughter with him. Inevitably this meant that there were often sustained periods of time when they would not see each other. This is something that caused great distress to GRO-B P and myself. P s Hepatitis C infection and the catastrophic decline of his physical and mental health robbed GRO-B of the once day to day contact she would have with her dad.

44. In particular in the last 4 years of P s life my own health began to suffer, I had a daily battle with insomnia and had almost constant worry about P s declining physical and mental health, at times I felt it overwhelming to cope with the worry of P along with being a single mum working full time with a house to keep. I had to make GRO-B my number one priority and do my upmost to protect her from the horror of P s Hepatitis C infection. This meant I wasn't always on hand to be with P as much as I may ideally have wanted. To this day I live with guilt that I could not offer more support and help to him when he was going through this hell.

45 GRO-B lost her dad 5 days short of her 11th birthday. I had to wake her and give her the news when I returned from the hospital after P s death. I had

made the decision not to take her to the hospital when I knew he only had days to live as he was unconscious and it was not what P would have wanted and not how I wanted her to see him for the last time.

46. GRO-B was devastated but really at that age she was too young to be able to process the grief properly. She was so brave and tried her best to adjust to her new life. And so, began the years of Christmases, birthdays, fathers' days, happy occasions and sad occasions all without her dad being there because his life was stolen prematurely. When she passed her exams, she couldn't ring him to tell him. When it was her prom night he wasn't there to look on at her so proudly. In the 7 years following his death she just tried her best to get on with life despite obviously missing him terribly. Her 18th birthday arrived and we had a massive party to celebrate, she went on an amazing holiday and we bought her everything she could have dreamed of. But turning 18 without her dad there I feel was like a catalyst for her and the grief that had been supressed for so long hit her like a truck. She has had up and down years but since then she has suffered periods of low mood, she has self-esteem issues and other issues with anxiety which we feel sure stem from the trauma of losing her dad so young. The loss of her beloved dad has cost her so much in life and along with P she is the biggest victim in this.

47. P s work life began to suffer from when he started to take Interferon for the first time. The severe physical side effects, insomnia and lack of concentration made it very difficult for him. Along with this, his low mood and mood swings changed the whole dynamic of his work life. Prior to diagnosis he was a focussed and ambitious leader in work but after his diagnosis this started to rapidly disappear. As his health deteriorated his sickness absences increased and resulted in him being finished from work in 2002. He never worked again after that. This caused him major financial problems and added to his stresses in life. On several occasions his house was threatened with repossession as he fell behind on the mortgage payments. He was having to survive on benefits and at the time of his death these amounted to just £600 per month. This was a further hit on P s dignity as he had never claimed benefits and he had never had to live in such a hand to mouth manner.

48. My work life was affected at times over the 10 years from P s diagnosis to when he died as I suffered from chronic insomnia and stress relating to concern for P 's physical and mental wellbeing. At times when P was very unwell my concentration in work suffered considerably and particularly in the final three years of his life when he was spending prolonged periods of time in hospital.

49. Financially, once P ceased employment, he was obviously unable to assist me as much financially with child support for GRO-B although he always insisted on giving me whatever he could out of the pittance he received in benefits. He was a proud and honourable man. A big financial impact was also that I had to pay for after school and holiday childcare for GRO-B as I had to work full time. Because of P s declining physical and mental health I unfortunately could not rely on him to be fit enough to care for GRO-B in the school holidays.

Section 6. Treatment/care/support

50. The only difficulty that I am aware of in P obtaining treatment was when he enquired about starting Interferon again around 2000 and was told that this may be a problem as he had been previously unable to sustain a 12-month course. Also, he was told that a decision would have to be made on application to the local authorities for them to decide if they would fund the treatment.

51. Counselling was not offered to P or me when he was given his diagnosis. The only record that I can see of psychological support being offered to P was around 2003 onwards when his alcohol dependency and depressive state had begun to be a much bigger issue in his life. I have found no evidence of P ever being offered counselling for the fact that he was infected with Hep C and I feel this is something that was most certainly needed. In P s final year of life we talked a lot about his Hep C. At that stage neither of us had any idea of just how many people it had affected. He always said he felt so disappointed that no explanation was ever given to him

for it and in his words 'no-one even seemed bothered that his life had been destroyed in such a way'.

Section 7. Financial Assistance

52 P received a Stage 1 payment of £15,000 or £20,000 in or around 2004 from Skipton Fund. He was alerted to this by his regular haemophilia nurse.

53 P received a Stage 2 payment which I believe was £25,000 in approximately 2005 from Skipton Fund. He told me he had to fill in several forms to receive the payment and it was relatively straight forward. P did not receive a regular monthly payment.

54. In 2011 after contacting the Skipton Fund I was told P s estate was due a further Stage 2 top up payment of £25,000. I had to fill in several forms and send them P s Will, Grant of Probate, Death Certificate and various forms of identification for myself. I was then paid the £25,000 as Executor for me to distribute in accordance with his Will. It was a relatively straight forward process.

55. I contacted the Caxton Foundation in or around 2013 after being told they may be able to offer some financial support for GRO-B who was still a minor at the time. I found them to be rather guarded and was told they can offer some discretionary help but could not give me examples of what it might be available for. I found this a little awkward and embarrassing. I eventually asked them for help towards winter clothing and shoes for GRO-B I was then sent various forms asking for payslips for both myself and my partner and detailed income and expenditure forms to complete. I found it to be quite invasive and very probing but decided to go ahead with the request as we were struggling financially. I felt GRO-B should not suffer as a result of this. I was then told I would need to purchase the items and send in receipts and, only at that stage, would they determine if they could offer payment. Eventually after receiving receipts they agreed to pay approximately £350.

56. A further request was made when GRO-B s laptop that she used for her education broke. This time the process was easier as they used the income details I had submitted some two years earlier and payment was made within approximately 14 days from applying.

57. Whilst I appreciate, they need to be careful with the funds they distribute I did find the whole application process a little demeaning and it did prevent me from making other claims when I needed assistance.

Section 8. Other Issues

58. I have no other issues that I wish to add except that I have not had full disclosure of the entirety of P s medical notes and records.

Anonymity, disclosure and redaction

59. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I do not want to give oral evidence.

Statement of Truth

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

Signed GRO-B ....

Dated 16/3/2019.

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This witness statement has been prepared without the benefit of access to P's full medical records. .

2/6/1980 _ First record of cryoprecipitate
22/05/1981 _ Last record of cryoprecipitate (dental treatment)
20/08/1982 _ First record of Factor VIII given
20/10/1982 – 22/10/1982 – Factor VIII given
28/12/1982 – 29/12/19982 – Factor VIII given
21/2/1983 – 24/2/1984 – Factor VIII given
07/03/1983 – Factor VIII given to treat bleed in Hips.
29/8/1984 – Factor VIII given following nightclub assault.
28/6/1985 – Factor VIII given for hamstring pain/muscle bleed.