Witness Name: GRO-B
Statement No:WITN1240001
Exhibits:WITN1240002-5
Dated: April 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 and I was born on GRO-B 1963. I live with my partner at GRO-B GRO-B. I have two children and a grandmother of three boys. I was employed in children services until I was made redundant in 2012.

2. I make this statement as the partner of GRO-B: P who was born on GRO-B GRO-B 1946 and died on GRO-B 2004 as a result of infected blood products. We had been together for over 20 years and I was the executor of his estate.

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

Section 2. How Affected

4. I first met P in 1981 and we were together until his death in 2004. We had two sons from our relationship. We had our first son in 1982 and we moved into our first family home in GRO-B 1983.

5. P suffered from mild Haemophilia A with a clotting factor of 12%. He rarely required treatment.

6. In May 1983 P was admitted to GRO-B Hospital for a routine hernia repair and received Factor VIII injections twice daily for the duration of his stay.

7. I attach as Exhibit WITN1240002 a copy of his treatment record from the haemophilia centre. It is the Factor VIII treatment in 1983 which I believe was responsible for his infection of Hepatitis C (HCV).

8. He received most of his treatment from GRO-B Hospital under the care of Dr GRO-B and Dr GRO-B, and from 1987, Dr GRO-B. We were given no information or advice regarding being exposed or at risk of infection through the blood products he received.

9. It was sometime in June 1983 that we were advised that P had contracted hepatitis non A non B, after various blood tests. When we asked how he had contracted it they were very vague and said that they really did not know how. They did not tell us much about it: I got the feeling they were not sure what they were dealing with other than it was some form of hepatitis. We were never given an explanation as to how he had caught it. I attach as Exhibit WITN1240003 a copy of the test result.

10. I remember being told that there was a small risk to myself and our young son but to err on the side of caution and it would be advisable to use separate knives, forks, towels and flannels. We were told not to have sexual contact and he was advised not to have close contact with our one year old son. As

long as we washed our hands and did not have close contact we were told that we would be OK. They said that once he was no longer jaundiced that it would be fine and he would not be contagious anymore and we could carry on as normal.

Section 3. Other Infections

11. I am not aware of any other infections besides Hepatitis C (HCV) formerly known as non A non B hepatitis.

Section 4. Consent

12. I remember that my partner was not told the source of the Factor VIII he was treated with. He was not told that he could be at risk of infection from it.

13. I was not aware at the time that he was ever treated without consent. However, I now believe that he was used as a PUP (previously untreated patient). It was the first time he had received Oxford Factor VIII at GRO-B.

Section 5. Impact of the Infection

14. Shortly after receiving Factor VIII treatment in May 1983 he started to develop flu like symptoms and then he started turning yellow. The whites of his eyes and his body were tinged yellow and he was continually nauseous and would often vomit. His urine was orange and his stools were very pale in colour. P became very lethargic and fatigued and spent a lot of time inside resting as he struggled with day to day living. The hospital told us that he had contracted Hepatitis but was unclear which one and would be doing further tests. I asked if it was Hepatitis A and how he could possibly have caught this while being in hospital. They would not say for sure what type it was and how he had caught it but to treat it like Hepatitis A.

15. We were told to abstain from having sexual contact until he was no longer jaundiced. I looked after our son as well as nursing my partner and this continued for quite a few months. He slept in our son's room and my son slept with me in our room.

16. P took a good six months or so to recover and even though he was no longer yellow he was continually exhausted which resulted in him being sacked from his job with a building company. Whilst he still was off sick and with supported sick notes they felt that he had become unreliable. I had managed to get a part-time job which helped us a little and it meant I could look after P and our son with a little help from my family.

17. In February 1984 P went into hospital again for dental extraction; this time he had no issues and recovered well.

18. In GRO-B 1984 our second son was born 6 weeks premature. After a week in hospital we were allowed home. P was alright at this stage although still struggling with lethargy and fatigue and was struggling to get back into employment. Eventually he secured another job but only for approximately one year because he struggled to cope and was exhausted so eventually they had to let him go.

19. P was out of work more often than in and on the occasions he managed to find work it was always short lived to the point of just starting to feel like we were getting back on our feet to being knocked back down again. I ended up going out to work and managed to get cleaning jobs early in the morning and in the evening to help out financially but had to give the morning job up as P was struggling to get out of bed and I was concerned for the welfare of my children. We had to claim benefits to be able to get by and this continued to be our way of life for some years.

20. My brother in law was also a haemophiliac but he was quite severe and required regular home treatment as the slightest knock to him would cause a bleed. I remember that he and my sister had come to visit us early in 1986 and they told us that he had been infected with HIV through his treatment of

Factor VIII. I felt sorry for my sister and her two children and considered ourselves lucky that P hadn't contracted it as they had been in hospital at a similar time. We did not connect the Hepatitis with P's treatment of Factor VIII. As far as we were concerned as he was not jaundiced anymore, we had been led to believe he had cleared it with no onward complications.

21. P managed to get a temporary job but in GRO-B 1993 a few months into the job he tore a muscle in his thigh he was hospitalised for 16 days requiring Factor VIII. His recovery took several months and unfortunately he lost his job with GRO-B.

22. He was able to secure other employment and was earning a decent wage; enough to enable me to stop work. We decided to book a holiday abroad as we had never been on holiday as a family. However, after 18 months of working despite struggling with fatigue he had lost a lot of weight and looked extremely ill; he lost his job again. The holiday fell through and we lost the deposit of £300 which to us then was a considerable amount of money. He was taken back on at work about 6 months later but this time he really struggled to cope with it all and his position was terminated. We then continued on benefits.

23. P had not been to see his consultant for some time because although he still suffered from lethargy and fatigue; he generally felt well and had no haemophilia issues. He was not working so was able to manage better and he didn't like fuss. It had been agreed previously with his consultant that as he was only a mild Haemophiliac he only really needed to see him when he had an issue and he could just make an appointment. Several appointments had been made by the hospital for him to attend. However they sent no explanation as to why and as P felt alright he did not attend.

24. In October 1995 they sent a letter to us explaining that the Non A Non B Hepatitis he had caught was in fact Hepatitis C (HCV) and that he needed to come in as soon a possible. I attach a copy of that letter as Exhibit WITN1240004. We made an appointment immediately. I remember that P had been sent appointments prior to this but we did not go as he did not

need treatment. If we had known that the general appointment were related to HCV infection we would have attended immediately.

25. In January 1996 I was tested for HCV which fortunately was negative and the consultant said that if I was clear then our son would also be fine too. This was a huge relief.

26. In February 1996 P was admitted to hospital for a liver biopsy. It was established then that P had cirrhosis of the liver which was a complete shock to us both. I thought that this condition was only related to drinking excess alcohol.

27. P hardly ever drank alcohol; it made him feel physically sick. The consultant did question him on his drinking almost looking for another reason to blame the cirrhosis on but realised that he could not as P hardly drank at all. I remember his consultant saying to him that he would have to have been drinking several pints and a bottle of whisky every day for years to have cirrhosis to the extent of which he was suffering and he realised that he could not blame it on that.

28. At this stage we were not aware of how serious this was and what it would lead to. P was put on a 3 month course of Interferon injections three times a week to try to combat the Hepatitis C infection. Initially he tolerated this pretty well to the point his levels in the blood test were undetectable and he appeared to be in remission. The treatment was stopped.

29. Unfortunately, he had a relapse and the Hepatitis C came back.

30. By June 1997 P was back on a course of Interferon injections three times a week along with a course of Ribavirin tablets. In the beginning he tolerated this combination quite well but after a couple of months he started to feel nauseous and retching to the point of being violently sick. He became very difficult to live with; snapping and snarling at not only me but the children. We were constantly arguing. We put this down to the Ribavirin drug as previously

he had tolerated the Interferon quite well aside from the soreness he suffered at the injection site.

31. From 1998 P was in remission and all side effects from the treatments seemed to subside although he still suffered from lethargy and constant fatigue. Financially matters were bleak but we managed to muddle through and continued to get on with our lives; taking each day in our stride.

32. In 1999 after several interviews with the job centre and back to work assessments the benefits agency decided that P was really unfit to work and was awarded Incapacity Benefit. We were advised to make a claim for Disability Living Allowance but he was refused on the grounds that he could feed and dress himself so we didn't try for this again.

33. In February 2002 I started a new job and I was able to support the family fully. It appeared that things were starting to improve. Although P was still suffering lethargy and chronic fatigue he said he felt generally well. He did not look well; he appeared to have gained quite a significant amount of weight.

34. In April 2003 we decided to take advantage of the fact we could buy our home from the Council as the mortgage payments were cheaper than the rent and for the first time in our lives we felt life was really starting to move forward and the cloud that had hung over us for years was lifting. We submitted our mortgage application form but because of P's condition we decided the insurance payments would be too high so I decided it would be best for it to be in my name only.

35. In April 2004 we owned our own home and began to make improvements. Over the next couple of months we stripped every room. However, during this time I had to rush P to A & E as he was struggling to breathe and had pains across his chest and shoulder. He also developed a rash over his body which the doctor on call had noticed but this was dismissed as irrelevant and the doctor decided that P was suffering from a muscular problem; he was discharged.

36. A few weeks later P got niggling pains in his left side and a constant stomach pain that he could not get rid off. He went to see his GP. He told me that on his way to his GP he had met a man who he had started chatting to. This chap had also been suffering from stomach ache which turned out to be cancer. This did freak P out a little as he had had the niggling pain for some time. The GP told him that he did not know what was wrong with him and told him to try painkillers and to see how he went. Although they did help the pain, it didn't get rid of it. However, P didn't go back to his GP as he was due to see the consultant so he carried on trying to manage the pain.

37. On 5th August 2004 we went to see the consultant who examined P's stomach. He said that he did not feel anything was wrong but that he would send him for an X-ray. We went back later to get the results. The consultant indicated that there appeared to be a blockage in his bowel.

38. P now was beginning to really struggle and was taken into hospital to try and sort the blockage out. He was put onto an oncology ward but I didn't think anything untoward at the time as haemophiliacs were often put on to different wards as they did not have room on their own ward.

39. P was taking lactulose. Unfortunately no one had told him to dilute it and he was going to the toilet too much. We were still totally oblivious as to what was wrong with him. Eventually he had a CT scan. The machine had been broken and his appointment had been put back a few times. By this time he had been allowed home.

40. Around the bank holiday weekend P looked terrible; he was in a lot of pain in his back. He could not bear anything touching it; not even his pyjamas. Whilst we were due to see the consultant to discuss the CT scan results after the bank holiday P was screaming in agony one night and woke me up. I immediately phoned the ward that he had been discharged from but they refused to take him and said that I should go back through A & E. I phoned for an ambulance and he was admitted once again.

41. Unfortunately I was unable to attend the hospital with him as workmen were arriving to fit new windows and I had to be at home to let them in. I received a phone call from P later that morning who said that they had found a shadow on his liver. At this point I broke down; I was completely devastated. This was extremely awkward for the workmen who were in the house fitting the windows.

42. I went to the hospital later that day feeling that my world had fallen apart. After further investigations and scans it was finally established that P had a 12 cm tumour on his liver, a massive tumour situated between his stomach and back and spots on his lower spine. He was now in a very bad way.

43. He was kept in hospital and never returned home.

44. He was started on radiotherapy but this made him violently sick and appeared to be a complete waste of time as by then he was far too ill. I kept asking the doctors how long he had got left thinking that there may be some chance we could bring him home for one last Christmas. This was his favourite time of the year. All the doctors would say was "how long is a piece of string"; they did not really know. I am sure now that they did know but they would not tell me.

45. Two weeks after he was admitted he seemed to deteriorate rapidly. He was on high doses of morphine and other drugs to dull the pain. On his birthday I went with the boys to spend the day with him at the hospital. We had a nice day although it was not easy. We were able though to talk about his funeral and the music he wanted when the time came. This was extremely upsetting.

46. P was deteriorating rapidly now and the doctors decided that they could do nothing more to help and decided that P should be moved to a Hospice. His consultant took me to a room and said to me "I have let P down. I should have picked this up a lot sooner. I am getting too old for this; I think I need to retire". He also mentioned something in his blood the year prior was higher than normal but this had been overlooked. After P died I was speaking with a haemophiliac who was infected with HCV and he advised

me that he constantly received loads of checks on his liver. My partner should have been receiving these checks too and was seriously let down by his consultant.

47. On Wednesday 22nd September P was transferred to GRO-B GRO-B. He was alert for a couple of days and was on a driver to combat the pain. He now struggled to walk so I was taking him out to the garden in a wheelchair. He was becoming very twitchy and unable to hold cups and plates.

48. On the Thursday evening P had become very agitated and I was called at approximately 3am on GRO-B 2004 to go to the Hospice as they believed he was nearing the end of his life. When I arrived P kept trying to speak but I could not understand what he was trying to say. An hour or so later he slipped into a coma. I stayed at the Hospice with him all day and night; I did not want to leave him on his own.

49. P lasted three more days and I just watched and waited for the inevitable. He died on GRO-B. From actual diagnosis he had lasted less than 4 weeks.

50. We did not tell our friends and family about his infection as in those days there was a huge stigma with regard to haemophiliacs and HIV and we thought that people would assume that P had HIV too.

51. We kept the infection a secret. We did not tell friends or neighbours for fear of retribution. Initially we had not told our sons as at the time they were only young and would not have understood. During the latter years of P's life we did tell them and explained why their father could no longer work and why at times he was quite poorly. We tried to shield them as much as possible so that it would not impact on them too much.

52. The whole infection had a huge mental impact on P when he realised that he would never be able to work again. He would often feel like he had failed as he was unable to support the family; he had come from a family where the

man was the breadwinner and he felt he was letting me down. He was also depressed at times.

53. The causes of death on his death certificate were metastatic adenocarcinoma and hepatic cirrhosis secondary to chronic hepatitis C infection. We had never been told that people with hepatitis C are likely to get cancer. P had never been referred to a liver specialist. When P died I asked for a post mortem but this was refused. I could not understand that within 4 weeks of his diagnosis P was dead. I did not have any problems with funeral arrangements.

Section 6. Treatment/care/support

54. As we had not known about the impact of this infection until 1995 we were totally oblivious to the fact that there was a chance of cross contamination. We had not told any of our health professionals because as far as we were concerned he'd had some sort of hepatitis and was free of it. We had never told the dentist as the question was never asked but after we had been told, P did not visit the dentist again. Once we had been told, we made sure medical professionals were also very aware of it but we kept it secret from our friends and neighbours.

55. I believe that P should have been referred to a liver specialist for treatment once cirrhosis was established; he was never offered this nor any other treatment available.

56. No counselling or psychological support was ever offered. I did have some bereavement support from the Hospice when P died but this was with other people who had lost relatives from cancer.

Section 7. Financial Assistance

57. My partner received no financial assistance throughout his time of suffering.

58. We had heard on the news about the payments from the Skipton Fund and P said at the time "I'll be dead when that comes through". In October 2004 I received £20,000 by way of Stage 1 payment from the Skipton Fund and then I received two payments of £25,000 each as Stage 2 payments.

59. I found out accidentally about a bereavement payment through the Skipton Fund that I was entitled to. I read about it on the internet and realised that I had missed the cut off date of March 2016. At no time had I had been informed about this despite the fact that they had my up to date details and I asked them why they had not contacted me. They made some excuse that they did not want sensitive information opened up by someone else in case I had moved away. Fortunately, however, they did pay it and I received £10,000.

60. In 2017 I applied to EIBSS for income top up payments and I started receiving these from September 2017 in the sum of £750 per month. This will be increased this month (April 2019) to £917 per month. Whilst I did not find the application difficult I have to re-apply every year to continue receiving the payments which I find is unnecessary. A simple re-application process would be better. Although I am grateful for these payments, I only wish that we had received financial assistance during P's lifetime which would have eased our financial situation and made life a little easier for our family.

Section 8. Other Issues

61. I recall on a number of occasions when I went with P to the hospital for check-ups, the waiting area was in a corridor and we would sit outside the receptionist's office. I regularly saw medical files on the floor stacked two or three on top of each other and people's notes and blood results had been knocked out of the files by people brushing past and were just there to be seen by all. I remember thinking how odd this all was.

62. P and I did consider taking legal action in the 1990's with regard to his contraction of Hepatitis C through the contaminated Factor VIII but we were informed via our GP through a letter from his consultant that success was doubtful. I attach the correspondence between P 's GP and the consultant Dr GRO-B as Exhibit WITN1240005.

63. I again considered legal action for medical negligence after he had died. I felt that he should have received better care and attention from his consultant and that his illness should have been picked up a lot sooner than it was. I did not pursue this as I felt I was up against a brick wall when trying to obtain medical information and dates through doctors and GP's who were constantly questioning my reasons. I felt I was alone against a big organisation with people who just seemed to look after each others' backs. Equally I just wasn't strong enough to fight; I was grieving for P.

64. It has been extremely stressful trying to obtain P 's medical records. I have continually been given different excuses; from being told that they have been destroyed to then being told they have some electronic records. When I received these, half of the information was missing. I have chased again and again to be told that the records were destroyed in a flood. The hospital had black books in which they logged all of the treatments and batch numbers for Factor VIII given to haemophiliacs. The books from 1983 and 1984 when he was infected are both missing. I have spoken to a woman at the hospital who said that all of the records had been moved into a new building but some men had come in and removed certain records and they do not know if they have been destroyed or mislaid so I cannot get hold of that information.

Anonymity

65. I confirm that I would like to remain anonymous and that I understand this statement will be published and disclosed as part of the Inquiry.

66. I do not want to give oral evidence to the Inquiry.

64. It has been extremely stressful trying to obtain P 's medical records. I have continually been given different excuses; from being told that they have been destroyed to then being told they have some electronic records. When I received these, half of the information was missing. I have chased again and again to be told that the records were destroyed in a flood. The hospital had black books in which they logged all of the treatments and batch numbers for Factor VIII given to haemophiliacs. The books from 1983 and 1984 when he was infected are both missing. I have spoken to a woman at the hospital who said that all of the records had been moved into a new building but some men had come in and removed certain records and they do not know if they have been destroyed or mislaid so I cannot get hold of that information.

Anonymity

65. I confirm that I would like to remain anonymous and that I understand this statement will be published and disclosed as part of the Inquiry.

66. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-B ……………

GRO-B

Dated ...24./4/.2019......................