Witness Name: GRO-B
Statement No: WITN2900001
Exhibits:
Dated: August 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 of GRO-B GRO-B. My date of birth is GRO-B. I have just been made redundant from my job with the local authority where I have worked for GRO-B years, on the grounds of ill health.

2. I make this statement in relation to my late half brother, GRO-B: B who was born on GRO-B and passed away on GRO-B at the age of 47. He was infected with Hepatitis C as a result of receiving contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my late brother'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.

4. I am aware that my GRO-B, GRO-B and my GRO-B, GRO-B also provided their own statements to the Inquiry. Their witness numbers are GRO-B and GRO-B.

Section 2. How Affected

5. B is my GRO-B GRO-B is my GRO-B and I will refer to GRO-B and my mother as 'our parents' for the purposes of the statement.

6. B was approximately GRO-B years old in GRO-B or GRO-B when he sustained an injury to his leg whilst playing rugby GRO-B which caused severe bruising to his leg. The GP sent him to hospital and after a number of tests and investigations B parents were told B had some sort of clotting deficiency and he was diagnosed with Von Willebrand Disease (VWD).

7. We were told about a new wonder drug Factor VIII which was the missing blood component for clotting purposes, the hospital staff administered this via injection. There were no discussions about any risk or any mention of trials. B received this treatment in good faith from the medical professional and in particular the Haemotology Department at the Royal Shrewsbury Hospital.

8. Having reviewed some medical documentation recently since B death it appears that B blood count was borderline and it may have been that there was no real evidence to suggest that he actually needed the treatment.

9. I believe that the next occasion that B received Factor VIII would have been in 1986 following a GRO-B and then a few years later when he had

to have a further operation to remove the metal rod that was put in his broken leg at the time of the accident.

10. As far as I am aware B did not receive Factor VIII on any other occasions or for any other reason and certainly not in the years preceeding the first treatment.

11. No information was given to B parents (or B) at the time Factor VIII was given to him.

12. B was infected with Hepatitis C at the Royal Shrewsbury Hospital.

13. B in later years sadly referred to himself as a 'Labrat', 'Guinea Pig', or a 'PUP' which is a 'previously untreated patient'. He described himself as a patient who fitted the criteria of a young male adolescent who had not received treatment for haemophilia in the past.

14. In November 2005 B became very poorly at home and left his own home and went to stay back home with his parents. On the Sunday morning his mother telephoned me because she was so worried about him. I went round immediately and it took me moments as I lived next door. I took one look at B and immediately rang the out of hours GP service. I answered all their screening questions and they immediately despatched an ambulance which arrived within minutes. I remember when B was first examined by the ambulance staff and I was told B was extremely ill and in a very serious condition. The ambulance rushed him straight to hospital.

15. B was admitted into hospital and the staff worked very hard to stabilise him and it was many hours before we were able to see him. When we did he had blood going into both arms via a drip and he was wired up to monitors. He looked dreadfully poorly and the one thing I remember is amongst all his pain and suffering he looked at me and blamed me for allowing the staff put a catheter in.

16. The hospital staff told us that B had endocarditis which is an infection of the endocardium, which is the inner lining of the heart chambers and heart valves. We think it was to do with a tooth extraction that he had the week before and as a result of not being given antibiotics. B remained on intravenous antibiotics 4 times a day and stayed in hospital for 6 weeks. I thought that it wasn't so bad and after he had finished the course of treatment and he would be well again.

17. A few days into his treatment, we were told by B Consultant that his liver tests were very abnormal; we were asked if B was a drinker or a drug user. We were astonished and told him categorically that he wasn't either. The Consultant told us that B presented as though he had consumed at least one bottle of hard spirits daily. We told him that B ran his own business, worked long hard hours to make the business a success and drugs and alcohol certainly were not the cause of his condition. We were later informed he had been diagnosed with cirrhosis of the liver.

18. We visited B at every opportunity. I remember not long before Christmas I visited B on my own one Friday night and he was so very upset. He wouldn't look at me, wouldn't speak to me, and wouldn't let me touch him, or try to hold him to comfort him. He told me to go home because he wanted to be left alone and didn't want to talk to me. I left the ward and telephoned Mum who had visited earlier in the day and she said he had been fine that afternoon when they had left him. I was so puzzled by this drastic change in B and I was so upset that I left the hospital in floods of tears. I then telephoned our older brother GRO-B, and although it was past visiting hours he went into see B. GRO-B rang me much later that night to tell me that B had tested positive for Hepatitis C and that they had checked his records and it had been confirmed that he had been given contaminated blood in the 1980s.

19. I remember B being very quiet after that and he was allowed home for a few hours on Christmas Day but he was poorly and he didn't stay long. I took him back to the ward at the hospital. On New Year's Day he was again allowed home for a few hours and instead of wanting to go home he insisted on being taken to Curry's Electrical Store. He was clearly in pain and unwell. He sweated profusely and he was unsteady on his legs. We didn't have a wheelchair in those days and I wasn't expecting a visit to the New Year's Day sales. He made his way into the store and purchased a laptop and everything he needed to use it in the hospital. I later found out he wanted the computer so he could conduct his own research into Hepatitis C.

20. B never actually told me about his diagnosis until he was discharged from hospital following his 6 weeks of treatment. He gave me the leaflets that the hospital had given him.

21. There were no discussions that took place between me with anyone from the medical team on how B should manage the infection or precautions that he should follow.

22. B was infected during the 1980s and he only found out in 2005, which was over 20 years after he had been infected. If B had been told earlier maybe he would have received treatment earlier and been better monitored. Although B was not a big drinker perhaps he could have stopped drinking altogether. Everyone that B had come into contact with had been put at risk. So most definitely yes the information about his diagnosis should have been provided much earlier.

23. I realise that B was a grown up but I do feel that B should have had the opportunity to have a family member with him at the time he was told about the infection. I felt let down that the hospital had given him such devastating news and left him to get on with it.

Section 3. – Other Infections

24. We were never made aware of any of the risks and we had never really heard of Hepatitis C or the risks. Everything I found out about Hepatitis C was through my own research on the internet and not from any medical professionals.

Section 4. – Consent

25. I certainly believe B was tested for Hepatitis C without his knowledge or consent. I assume that consent for B to be given Factor VIII would have been given by his parents, but I can categorically say that they would never have given permission if anyone had discussed any risks with the treatment, and in particular in this instance B condition was not life threatening.

26. I absolutely believe that B was treated without all the information because no one in their right mind would agree to treat a child who didn't have a life threatening illness with a drug that was going to put them at risk of death.

Section 5. Impact of the Infection

27. The mental effect on B was very far reaching. He was a bright, intelligent young man of GRO-B years of age who clearly understood the implications of his diagnosis and had worked out that he had been used for research purposes. He knew that there was a risk of infection to others and he felt that restricted him pursuing a relationship and ultimately from becoming a father. Essentially he knew that he wouldn't be able to live a proper life. He had been told that with the extent of his cirrhosis he probably had a life expectancy of around 10 years. I do not think that B or any of us could get our heads around the fact that not only had he been used for research purposes, but cast out and left to deteriorate knowing that he was unlikely to see 50 years of age.

28. B suffered terribly with depression, he had awful mood swings, and he lashed out verbally at his family. I think he did this because he had no other way to let out his emotions.

29. There was no mental health support to help him deal with his emotions and no counselling had been offered to him to help him come to terms with his diagnosis. I believe there may have been a Hepatitis C group but from what B understood the people that attended were mainly alcoholics and drug users. B felt that their hepatitis was a lifestyle choice whilst his wasn't a choice and he had nothing in common with that group of people so he chose to stay away.

30. The stigma attached to Hepatitis C was clear for all to see as far as we were concerned. The reality soon became apparent because his childhood friends stayed away from the house and visitors became few and far between. Even B cousins who lived in the same village stayed away. B became very lonely and very isolated living back at home and I would go to see him when I came from work and at weekends but that wasn't enough and B needed more company.

31. He played out a lot of his depression on social media and I think that people felt unable or uncomfortable with his cries for help because they did not know what to say. B would post on Facebook that he wished the GRO-B would come and take him. Suicidal thoughts were very real and B spoke on many occasions of his wish to die and life wasn't worth living. He spent many hours in tears and needed to be comforted. B was into his heavy metal music and he would post songs on Facebook that sang about death and dying. People just didn't know how to respond to his open feelings of death. As far as I could see, it upset people and that isolated B even more because he lost his friends on Facebook when it was actually a cry for help and friendship. All B really wanted was to have a right for life like everyone else and importantly to be loved.

32. The physical effects on B were enormous. When he was GRO-B he had a GRO-B GRO-B which left him with left leg complications. The physical injuries that he sustained compromised his mobility and he was restricted in what he could do. As the hepatitis progressed and did further damage B suffered with Encephalopathy which meant that he was severely affected and restricted. He was unable to be left alone and unable to drive. When he had a bad attack he was unable to communicate and he was admitted into hospital on multiple occasions. It was so awful for B because he was continuously accused by the medical staff of being an alcoholic or drug user and it used to really upset him. Typically it was alcoholics that would present with his condition and he didn't like the fact that he was pigeon holed into that category.

33. B had a small umbilical hernia, which the doctors had agreed to repair, but on the morning of the hernia operation, pretty much when he was on the operating table, the surgeons decided that they wouldn't operate. We weren't told exactly why they wouldn't do the operation but it could have been due to risk of bleeding. In the end the hernia got bigger and bigger until eventually it was the size of a football hanging between his legs.

34. The Hepatitis C really took its toll on B. He was constantly fatigued and his joints ached and hurt. The liver damage meant that he itched and would scratch himself until he bled.

35. B suffered from 'Brain Fog' which meant he couldn't deal with things like filling in benefit forms or answering questions and he would get easily irritated if he couldn't fathom something out. He got really frustrated when he knew what he wanted to say but couldn't work out how to say it.

36. B was advised not to eat protein initially which seriously restricted his choices in food, on one occasion he was about to eat a meal whilst in hospital and a nurse came shouting down the ward 'what are you doing with that piece of

gammon on your plate' and took his hospital meal off him, the nurse was saying he shouldn't be eating protein, imagine the shame and embarrassment at such public treatment and humiliation, as a result, he continued to cut all proteins out of his diet and suffered with poor concentration and his mental health and low mood just got worse, no life, no alcohol and now no nice food to eat. He was later told that he could eat foods containing protein because protein was needed to prevent muscle wastage.

37. B had ascites, the abnormal build-up of fluid in the abdomen and he had to be admitted into hospital on a regular basis for an abdominal drain. The procedure was both painful and uncomfortable. On one occasion there was in the region of 18 litres of fluid taken from his abdomen. It was really painful for him. Prior to the drain, he could barely move in bed and was unable to sit up or get up out of bed. I have never been able to understand why the hospital left B in so much pain and discomfort for days on end before being they gave him a bed. There were occasions when he had been admitted into hospital to later find that the anaesthetist had gone home for the weekend and the procedure couldn't go ahead or there was no albumin ready or available. All this was such poor treatment of a young man who shouldn't have been there is the first place and at the very least he should have received far far better treatment

38. Reduced mobility and poor blood supply meant that B had leg ulcers and because he was unable leave the house. The District Nurses came to the house to dress his legs on a regular basis. We live in a GRO-B it was a constant battle to get the District Nurses to come to the house. On one occasion I had taken B myself to the surgery because it was on a Saturday morning. Shortly after I received a telephone call and I was told that if B was able to get to the surgery then they would not visit and he would have to make his own way to the surgery in the future. I worked full time and couldn't take him during the week and he really did need the home visits. Again this was another battle that we should not have to have fought, B was fortunate he had a loving

supportive family who would do their best to ensure he got the treatment he needed.

39. We found out about a drug that was used to help with the Encephalopathy but I am unable to recall what it was called. We asked if it could be made available to B but we were told that it was too expensive and he wasn't allowed it, again another brick wall and another battle with our CCG. Eventually and thanks to his last Consultant Dr Kara Rye, who persevered, he was prescribed it on the NHS.

40. B had to take large doses of lactulose which meant he had constant bowel motions and he was restricted to the house because he was afraid he would have an accident and soil himself. The same applied to urine as he had to take furosemide water tablets.

41. B deteriorated gently at first following his diagnosis and it wasn't until the 3 years prior to his death that his health deteriorated quite fast. We knew it and B knew it, his encephalopathy attacks increased dramatically, hospital visits became more frequent and he couldn't tolerate the high doses of lactulose. His itchiness increased and he failed the flap test, despite trying so hard to keep his hands/wrists still and level. The final six months of his life were so very cruel and I wouldn't watch an animal suffer the way he did. He was in so much pain, uncomfortable, so depressed, and he said on many occasions he wished he could die as his quality of life was no quality. His family provided him with 24 hour care. We got some help for a care package from our local Council, for but I believed B care should have been provided by the NHS and I argued for 'Continuing Healthcare' which after yet further battles we were awarded, which meant we had a bigger care budget and were able to purchase some night sits, which enabled his father to get some rest. Eventually B was admitted into the local hospice for management of his pains and symptoms.

42. When he returned home it was heart-breaking to see him. He was so weak that he couldn't move and he wasn't able to do anything for himself. He had little or

no appetite and the itching increased so badly that it ripped his skin to pieces. His legs broke down and fluid poured out of his legs due to his immobility. B fought desperately to stay alive and he was admitted into hospital for another abdominal drain which was an absolute disaster. The drain was inserted under a guided scan and B was brought back to the ward but the fluid didn't drain. After about 4 or 5 hours when the family arrived for visiting, B was terribly upset because none of the fluid was draining. Eventually the nurse asked if he was able to sit up and we helped him into a sitting position on the side of the bed. B looked down and the nurse had not turned the actual drain on, consequently by that point the blood had clotted around the drain site. That was the reason no fluid had drained and was complete incompetence. B kidney function was very poor and the medical team decided to push fluids through his body to try and get his kidneys to function properly. Instead the fluid ran straight to his legs and just poured out of his legs. His legs were so wet that the nurse's didn't even bother dressing them and they just left him sitting with disposable Kylies on the floor with his legs leaking into that. It was a total and blatant disregard for his dignity and it broke my heart to watch.

43. After that horrendous admission into hospital I contacted the hospice and thankfully there was a bed available. We got him back into the hospice and sadly in just under two weeks of his arrival B passed away.

44. B had been seen at the Queen Elizabeth Hospital in Birmingham where he was assessed by the team for a liver transplant. He was turned down for the transplant and I will always remember how I felt when I received the news because we were absolutely devastated.

45. B did eventually receive treatment for his Hepatitis C and it was so severe that it left him totally fatigued. He was left with aches and pains that were consuming and debilitating. I understand that B had been given a 12 month course of Interferon and Ribavirin. B went to the Princess Royal Hospital

and he saw the hepatitis nurse who was called Sandra Taylor. She injected him with the drugs and he had regular blood tests. After about 10 or 11 months into the treatment when his viral load had reduced immensely. For some reason the Princess Royal Hospital withdrew his treatment. The official reason was that B had not reduced the viral load sufficiently at the 6 month marker point and he had developed a small rash. B was convinced it was because they didn't want him to live and he was cast out again. He was not offered any form of counselling and basically he was told to live whatever life he had left.

46. At some point later B was offered another course of treatment and I injected B weekly with the drugs. I found it so hard because when I injected him it made him very ill for a few days. He would be so cold but feverish, shaking, nauseous with terrible headaches and so weak that he couldn't get out of bed. Unfortunately we were told that treatment was also unsuccessful and once again he was dismissed and cast out with no support.

47. In about 2013 B was offered a trial for his Hepatitis C at the Queen Elizabeth Hospital in Birmingham. B Consultant Dr Kara Rye organised for him to be part of the trial. The treatment was successful and B viral load became undetectable which we all thought was fantastic news, but we also knew that his liver had been very badly damaged and that the successful treatment might have been too late.

48. B faced so many obstacles and difficulties when it came to treatment. The medication for his encephalopathy was a classic example. The withdrawal of the Hepatitis treatment and the refused liver transplant are further examples. He was also refused the hernia operation. I really do think it was shocking that no counselling was ever made available to him.

49. When he became unwell the GPs didn't know how to treatment him. We were told that the family just had to 'sit it out at home' when B was in a 'coma like

state'. He wasn't even in this world when he had an encephalopathy attack and we were told that the hospital wouldn't treat him any different to what we did at home. Maybe that was the case but they had all the medical knowledge and the equipment to treat B if things went wrong. I recall one time when we were told to take him out of A&E in the early hours of the morning because he took up a bed when he was so completely out of it. I told the hospital manager that if she could get him home and into a bed then go ahead and do but I was not taking any responsibility. They even described B as 'Combative' in his notes during an attack. The problem on that occasion was he wasn't in control or aware of what he was doing. The staff contacted security and they stood by his bed. Repeatedly and on nearly every hospital admission B was asked when he had a drink last and what drugs had he taken. That continued despite the family speaking with PALS where we asked for a statement to be put in the front of his medical records and or on the computer screen to prevent constant assumptions and accusations because it was both embarrassing and highly offensive.

50. Discussions took place with the gastroenterology ward to operate a 'revolving door policy' which meant that B didn't have to go through A&E or MAU (Medical Assessment Unit) and he could be fast tracked straight to the ward and be treated. However in reality it very rarely happened and he ended up spending hours or days in A&E or on AMU until he was admitted on to the gastroenterology ward.

51. However it has to be said that given the NHS were aware of his diagnosis years before he was told, they should have been truthful and told him when it was first known and offered him treatment as soon as it became available. If they had B prognosis could have been very different.

52. B had osteomyelitis and had a re-occurring bone infection from his GRO-B GRO-B in 1986, and we knew that it was an issue when he was considered for a liver transplant. One of the Professors at Stoke Hospital agreed that if the

Queen Elizabeth Hospital agreed to the liver transplant then he would treat the osteomyelitis. B was refused the liver transplant which meant that he also wouldn't be treated for the osteomyelitis. The Professor felt that B had managed the bone infection for so many years and there was no real reason to go through the procedure and it was never done.

53. I do believe that if B had the hernia operation his mobility and quality of life would have been so much better.

54. B really suffered with the side effects of the treatments including fever like feelings, shaking, sweating, nausea and fatigue. He didn't know whether it would work and what would happen if it failed. He thought that he was a guinea pig and that he had been through enough through no fault of his own. He thought that life was cruel and that he had no life other than suffering on a daily basis.

55. As far as I am aware B didn't have any trouble accessing dental treatments and he had good strong white teeth. He didn't go to the dentist very often but when he did the dentist said that he treated everyone the same and used disposable instruments.

56. The GP's were very kind but didn't know how to help him. One of the senior doctors attended on an occasion for a home visit and said, "what do you expect me to do he needs to be in hospital".

57. The impact of being diagnosed with Hepatitis C for B was life shattering and life changing. The fact that he had been infected without knowing for over 20 years had a tremendous negative effect on him. He felt guilty that he had put us all at risk, particularly as he had osteomyelitis and medical dressings were a part of B daily life because he had a weeping open wound. He questioned whether he had unknowingly given this to anyone else.

58. At the age of GRO-B B had a liver that was seriously damaged and compromised and his life expectancy was cut short with a prognosis of only surviving for 10 years. He never went out socially again because of the risk of infection to others. He became isolated and completely dependent on his immediate family.

59. B never felt that he had the opportunity to have a girlfriend, a wife or a family instead he believed that any prospective girlfriend would run a mile if she knew his diagnosis. As a family we kept his diagnosis quiet for some time due to the stigma that was attached to Hepatitis C. He knew that Mum had passed the VWD onto him and it was hard for him not to feel some anger towards her. His friends kept away and even some of his family from the same village didn't visit.

60. B could see the deterioration in himself and I know that he found it very difficult and he said on many occasions that he wished he was dead.

61. For many years I was a carer for B and during the latter years of his life as he became frailer, more frightened and more dependent. I have very recently lost my job on the grounds of ill health and I suffer with depression, which is related to the death of B

62. The impact on me was extremely hard and these are feelings that I have never spoken about before because I didn't want B or my family to think that I resented B in any way because I didn't.

63. My older brother left home just after he left school. He then moved away to GRO-B and then to GRO-B. B and I were very close and we both stayed close in terms of location. We both eventually lived in the village where we were born.

64. When B had his GRO-B at the age of 18, as his older sister I felt it my duty to take care of him. He did eventually get back to work which

wasn't until 10 years after the accident. He went to work for the same company where I worked.

65. In November 2005 B collapsed with endocarditis most probably from a tooth extraction the week before and I thought we were going to lose him on that day. The medical professionals soon realised that he was not at all well and the tests that followed confirmed he had been infected with Hepatitis C. Given that it was the most devastating news for B and that he was told just before Christmas 2005 he kept it from the family until the New Year. I knew something was wrong on the day he was told because of the way he behaved when I visited him.

66. Once home, in the New Year he did tell me, and from that day I vowed to be there for him come hell or high water. I went to most appointments with him depending on my work schedule but to be fair my work were very good to me in that respect.

67. When B had his treatment of self-injection at home it was me who used to inject him and he would curse me like mad on a Thursday night which was the night of the injection as we all knew the following 24/48 hours would be awful as B would be ill as the treatment did its thing. At that time I reduced my hours to 4 days a week so I could be at home on a Friday to support him. He was by then living with his parents and his dad would be at work whilst his elderly mum couldn't support him because she couldn't get upstairs to him.

68. In terms of my financial position that hurt me quite badly because as a single person living alone I missed the money. However I couldn't and wouldn't let my family know that it was a problem. I think I only worked 4 days a week for about 3 to 4 years but I had to return to full time hours when I changed my job in 2009 because it required me to work 5 days a week.

69. After the first treatment was withdrawn B tried to buy the treatment privately but the health authority wouldn't support him. It was so hard to see him so

devastated and I felt useless because I couldn't do anything for him except be there.

70. To watch the second round of treatment fail was truly horrendous and it broke my heart every day when I went to visit him. I went in every night after work to see him and I used to cream his legs, empty the commode and we used to chat about my day. It was so hard to leave him because he was so lonely and just wanted me to stay and talk or watch a film. He usually had some good film or TV programme to watch. It was usually way after 7pm when I got in and I then had to start on my tea and life became hard sometimes.

71. I went with B to so many hospital admissions, emergency admissions, arranged admissions and visited him on the ward. As his illness progressed and he suffered more and more hepatitis encephalopathy attacks we tried as a family our very best to manage him at home. It wasn't always possible and off in the ambulance he would go. We always went with him because during those attacks he wasn't able to speak and he wouldn't have been able to answer any questions.

72. When B returned he needed 24 hour care and after a couple of falls it was decided that he really couldn't be left alone.

73. B meant everything to me and I put him ahead of everything else in my life including my work and my personal relationship. My relationship with my partner broke down, although B wasn't the entire reason it didn't work but I couldn't offer what my partner needed and we just grew apart.

74. B was a big lad and when he had an encephalopathy attack he was very physical. He would throw his arms around, but he didn't mean to do it and it was all part of the illness and not B fault.

75. I found it mentally and emotionally heart breaking and it devastated me. I feel guilty that I should have done more and that I could have done more. I think

about the times I was short tempered with him and how that made him feel. I have so much regret and a feeling of utter guilt despite all that I did for him.

76. B got to the point where he needed help to mobilise to the commode and to help him on and off. He couldn't wipe his bottom properly or wash his private parts.

77. I can't say that we knowingly received any direct stigma, it was the subtle things like B friends staying away that hurt me the most because he was lonely enough without suddenly being made to feel an outcast. No one ever said anything detrimental in my ear shot anyway.

78. My mother carried the guilt of passing the VWD onto B and it did in my opinion almost break her. She was always a very strong lady and B was her outright favourite, if B said black was white she would agree with him. She doted on him, spoilt him and he was the apple of her eye. For her to see him deteriorate and struggle the way he did particularly the episodes of hepatitic encephalopathy nearly destroyed her and she would weep for hours and days.

79. I am glad that my mother didn't live long enough to see B suffering in the last years of his life, because if he had died before her she would have given up and died of a broken heart. Medical information that we have subsequently seen questions whether B did suffer with VWD at all. If that is the case my mother may have suffered and agonised over something that wasn't the truth.

80. B and his dad used to go out together on Sunday lunchtimes to the local pub but once he was diagnosed B never drank again and stopped going to the pub. Dad carried on going for a little while but without B he stopped going also.

81. Although my mother wasn't so well in herself, GRO-B gave up work to care for them both. He did this before he was due to retire and he had to financially support himself until he was able to draw his pension. When mum passed away GRO-B

became B carer, morning, noon, night and through the night. B didn't sleep well and he would wake GRO-B up during the night when he became frightened or felt ill. GRO-B got little or no sleep and he provided all meals and company to B It was a massive weight for anyone to endure, and like us all, he took that responsibility on his shoulders.

82. The impact is immeasurable and I can't find enough words to describe the pain, anguish, upset, heart break, financial strain, emotional strain and the assumptions that we had to endure from the medical professional in A&E and on AMU. The loneliness that the family faced and the bleak outlook. It was very hard dealing daily with B emotions and his suicidal thoughts. His very dark moods, his tears, his despair, his begging for help but we couldn't do anything to help him. He used to cry out for friendship on Facebook and it was laid bare for the whole world to see.

83. Eventually B had to give up work and for years he lived on state benefits, invalidity allowance, Disability Living Allowance and the rest was the goodwill and the financial help of his parents.

84. B had worked in the family business, importing furniture from GRO-B and selling online to the UK market. When he became sick he was building the business up with his brother GRO-B and both were Directors in the business. The business was in its infancy and had B not become ill who knows where it could have gone. Business was good at that time but when B was unable to work it had a substantial effect on the business. GRO-B who was the GRO-B side of the business had to come back and remain in the UK whilst trying to juggle the GRO-B from GRO-B and run the GRO-B.

85. B had his own house but he wasn't able to live in it because he required constant care. However there were bills that still had to be paid but B wasn't able to face dealing with things such as bills once he became ill. He used to say what is the point is as I won't be here, and the bills just mounted up. I remember

that I paid off a £700 electricity bill for him. Without a doubt B parents subsidised his living.

Section 6. Treatment/care/support

86. The GPs didn't know how to treat B, they were kind enough but of little use on a day to day basis, or in a crisis, when we tried to get him admitted.

87. I believe that any kind of psychological support for B was extremely limited. His emotions, suicidal thoughts and very black moods were always down to our family to manage. There were far too many times to recall, where I thought B wouldn't be with us in the morning as his thoughts about wanting to be dead were far too real and uppermost in his mind.

88. B did have a few (3 or 4 maybe) counselling sessions at a centre called the Hamar Centre at the Royal Shrewsbury Hospital, but this was primarily for terminally ill patients, and by that I mean generally cancer patients. B felt that they didn't understand him, as he had been given his life limiting illness by the NHS because he had been treated as a 'lab rat' human Guinea pig, (PUP) and not just by unfortunate bad luck as with an illness.

89. From our family perspective we were never offered any assistance and we were left to deal with it, no mention about how is affected us, we just had to keep going and be there for B The support for family was very poor given that we were expected to provide, 24 hour support to a dying man in such tragic circumstances. To this day I struggle to deal with the guilt and the emptiness I feel and this impacts my life on a daily basis. I tried accessing counselling about 6 months ago. The service did a telephone consultation and said they would be in contact but I'm still waiting.

Section 7. – Financial Assistance

90. B received the Skipton Stage 1 and then Stage 2 pay-outs. I believe from recollection this was when he was first diagnosed. I believe that this information was given to him by one of the nurses at the Princess Royal Hospital. I would assume that Stage 1 payment would have been in 2006, but I can't recall the year of the stage 2 payment at all.

91. I completed all of B applications for sick pay, invalidity payment, DWP, and these forms were always lengthy to complete. Although I don't recall there being difficulties or a problem with the claims being agreed.

92. When B was unable to wash himself or access the over bath shower, we asked for financial assistance to have a shower cubicle/wet room but this was turned down. Instead he continued with the indignity of having young female carers wash him on his bed.

Section 8. Other Issues

93. I want to know why all this was done, especially when they were advised not to use the blood products they still did and I want to know why.

94. I want to see someone held accountable for this and whoever made these decisions.

Anonymity

95. I wish to remain anonymous.

96. I do not wish 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 ....

Date... 19 - 6 - 2019 ....