

ANONYMOUS

Witness Name: GRO-B

GRO-B

Statement No.: WITN3879001

Exhibits: Nil

Dated: 15th / Feb / 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules, 2006 dated 14th November, 2019.

I GRO-B will say as follows:-

Introduction:

1. My full name is GRO-B and I was born in GRO-B 1937. I am a retired counsellor and live with my husband of over sixty years, GRO-B: H at our home in the South East of England. H worked in local government but took other jobs to support us financially, even supplementing his pension by working as a taxi-driver.

ANONYMOUS
- ANONYMOUS -

2. My husband and I had four children together, a daughter (the eldest) and three sons. I understand that my daughter wishes to remain anonymous in so far as the Infected Blood Inquiry is concerned, and although I have no wish to remain anonymous myself, I shall respect her wishes and ask that none of our names are publicly revealed and that they be redacted from this witness statement.
3. For personal reasons, my daughter wishes to remain anonymous and I respect her wishes, but whereas my sons and I are quite open about things, she is also a mother of five and a grandmother.
4. I grew up in GRO-B where having met and fallen in love with my husband H (1937), we married on GRO-B and settled in the GRO-B. A few years later we started our family, and were blessed to have four adorable children, first our daughter, and then three sons.
5. All four children were born in the family home, with a nurse in attendance; GRO-B: D our eldest (born: GRO-B 1962), GRO-B 1963), GRO-B: S2 GRO-B 1965) and GRO-B: S3 GRO-B 1968).
6. Our daughter was born a carrier of haemophilia and she became infected with Hepatitis C (which is also known as 'Hep' C' or 'HcV') as a result of her having received a blood product when having her tonsils out, as well as having one injection of Factor VIII before having a tooth extracted. This latter one was given at home, as instructed by St. Thomas' Hospital, using Factor VIII that had been supplied for the use of S2 and S3 who are both severe haemophiliacs.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

7. Our eldest son, did not have haemophilia, but his two younger brothers were born as severe haemophiliacs, a lifelong genetic condition they inherited, and they each suffered subsequent viral infections as a direct result of the haemophilia treatment they each received.
8. S3 was infected with Hepatitis B (also referred to as 'Hep' B' and / or HbV). Both S2 and S3 were infected with the Human Immunodeficiency Virus (also known as 'HIV') as well as Hepatitis C. Additionally, each has been told that they were exposed to variant Creutzfeldt-Jakob Disease (or 'vCJD') and S2 has a damaged liver, this having progressed to Active Micronodular Cirrhosis.
9. Our daughter and youngest sons were infected as a direct result of their having used a blood product known as 'Factor VIII,' and I will now seek to detail the manner in which they became infected, the impact it has had on both their, and our lives together, and the affect it had on their own families and friendships.

How Infected & Impact:

10. All of our children were born at our home GRO-B Prior to our having decided to have children, neither my husband nor I knew anything about haemophilia. Unbeknown to us, and to me in particular, I had been born as a carrier of haemophilia and could have passed on the condition to any of my children.
11. If I were to pass the gene on to a son, he may have developed haemophilia, if I had passed it to a daughter she may have become a carrier, like me; but at the time I didn't know this.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

12. Historically, I had experienced problems with heavy nose bleeds and also experienced clotting issues when having to have teeth extracted. I have been told, but did not then know for myself, that at the age of just nine, I had almost bled to death whilst having my tonsils extracted – but I didn't know what haemophilia was, had no haemophilia diagnosis myself, and in the absence of any other family history, was blissfully unaware that I was a haemophilia carrier.
13. At first, all was well with the children, health-wise, each appeared to be growing and developing as they should, but as time progressed, my husband and I noticed that the two younger boys, occasionally experienced painful joints and muscles which on occasions caused them both to limp when this involved their lower limbs, and especially their ankles.
14. Although we had no appreciation of it at the time, each time this occurred the boys were suffering a bleed into their joints as a result of their having haemophilia.
15. Whenever it happened, they were taken to see our local General Practitioner (G.P.), a Dr GRO-B who worked from a small group practise (with about three other G.P.'s) in GRO-B or they would be taken to our local general hospital, then the GRO-B Hospital in GRO-B GRO-B (this hospital, as it was, no longer exists, having long since been replaced by The GRO-B Hospital).
16. Nothing 'untoward' was ever diagnosed on these occasions, be that at either the G.P.'s or in the GRO-B Hospital, and at times I found the medical staff to be 'dismissive' in their approach to me and the boys issues, putting their limping down to some form of 'attention seeking' or them simply copying someone they may have seen walking badly to gain some form of advantage for themselves.

- ANONYMOUS -

17. It would appear that they didn't know about haemophilia or understand how it may present itself, and as I didn't know myself, I couldn't query their clinical decisions.
18. However, I believed and remain convinced to this day, that no one knows their children better than the mother, and I *knew* that something was wrong – they would often each be reduced to tears as the pain they experienced was so bad, and I knew that their condition wasn't natural. Our eldest son was fine, he didn't experience the problems of the other two boys, so I had someone to compare them against; and our daughter, although a carrier (albeit then unknown) equally displayed no outward signs of this condition.
19. When S2 had been about four years of age, whilst playing with his brothers as all boys do, he bumped his mouth and in so doing loosened two teeth. This caused blood to continually ooze from the gum. I consulted our dentist (a Mrs GRO-B of the GRO-B Dental Surgery).
20. The dentist examined him and initially thought, as I had, that *"things would settle down and the teeth tighten,"* so we left, but a few days later I had to take him back as the teeth were still loose and he was still bleeding from the gums, and she found herself compelled to extract both teeth
21. These dental extractions caused a great deal of bleeding, and with this he became increasingly drowsy. We were worried about this, and took him to the hospital in GRO-B from which he was transferred by way of referral to the GRO-B Hospital in GRO-B West Sussex - as at the time they apparently specialised in dentistry and dental problems.

ANONYMOUS

- ANONYMOUS -

22. Whilst in GRO-B the hospital staff, having formed the opinion that it was a dental matter and nothing more, took no steps to alleviate his bleeding or its associated drowsiness, and simply transferred his case. We were told to take him to GRO-B and so I found myself having to ask a friend to take us to the GRO-B Hospital by car, despite his continuing to bleed out and becoming progressively drowsier.

23. By the time I had taken him into GRO-B he had already been bleeding on and off for some three days. It was quite apparent to me, and should have been equally apparent to the hospital staff in GRO-B that he was in a pretty bad way, but they took no further action other than to conduct a quick examination and refer us on to another hospital. He was 'someone else's problem,' not theirs.

24. I believe their efforts were lacking, they did not investigate his condition as fully as they should have done, and took no steps to alleviate his bleeding or the conditions presented immediately before them. With the benefit of hindsight, I do not believe that my taking him on to GRO-B myself was appropriate under the circumstances - he should have been given an ambulance transfer with suitably qualified personnel on hand should he take a turn for the worse.

25. Once at the GRO-B Hospital, it was found that he had lost so much blood that he would have to be admitted. He was kept in for several days, both being treated and observed, until his condition had improved sufficiently enough for him to be transferred back to the hospital in GRO-B so that he could be nearer to his family – with three other children, and one in hospital some distance away from where we lived, managing to care for all four and their respective needs was proving difficult.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

26. The staff at the [GRO-B] Hospital didn't tell me anything as to what was happening with my son, how they were treating him, or why - but they did ask if there was any family history 'to do with bleeding?' I knew of none, and told them that at the time, then to make sure I contacted my parents to enquire, but there was no past history that anyone was aware of.
27. [S2] remained in hospital in [GRO-B] until such time as they felt he had recovered sufficiently to be allowed home. However, throughout this time, no mention was made of haemophilia, and in so far as I was aware, no investigations conducted in that regard, so clearly it wasn't a condition which had appeared 'in their thoughts' as regards the root cause of his uncontrolled bleeding.
28. Just a few months later, our youngest son experienced such a swollen and painful ankle that he found himself unable to walk. I took him to the hospital in [GRO-B] where because he was also found to be running a slight temperature, he was admitted as an inpatient.
29. Upon examination, the medical staff noticed a lot of bruising about his body, commenting on it, and looking at me in such a manner as to make me feel guilty - as if I had in some way caused it, that I was to blame and either hadn't looked after him well enough or had consciously abused my child.
30. I felt dreadful, and was worried sick that they could think that I had been responsible for the bruising he had. I didn't know how they could think this of me, but truly believed that they did, and became even more worried when considering the implications for my husband and I, and our children, with them thinking that way - we could have lost the children to social services.
31. With [S3] as an inpatient, a clinical decision was finally made to test both of our younger sons for haemophilia. I certainly don't remember my having given consent, but they were both tested, and each was found, not only to be a haemophiliac, but to be severe haemophiliacs.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

32. We were then referred by [GRO-B] for haemophilia testing at St. Thomas' Hospital in London as a family, as the clinicians in [GRO-B] suggested that we should all be tested, which we readily submitted to. This was how and when we first discovered that both my daughter and I were haemophilia carriers, and testing confirmed that our two youngest sons were severe haemophiliacs. On a more positive note, such as it could be, testing showed our eldest son and my husband to be 'clear,' neither had it.

33. Having received these test results, we were told that we needed to register with [GRO-B] through whom a National Haemophilia Database was maintained, to ensure that our family was known to them and 'registered.'

34. As I have previously stated, prior to the test results being returned from St. Thomas' and the late interest of [GRO-B] which brought them about, I had no prior knowledge or understanding of haemophilia, the condition, how it manifested itself, how it could be carried or passed on, or any means of treatment, if there was one.

35. There was no familial history, and since their respective births there had been many episodes of what we now know to have been haemophiliac bleeds which had passed undiagnosed and ineffectively treated through both my G.P.'s practise and at the hospitals in [GRO-B] and [GRO-B] [GRO-B] Haemophilia hadn't even been mentioned before.

36. I began to research the condition myself, and in so doing learned a lot but at the same time became very concerned as to the future prospects for our two youngest sons, as what I found was frightening.

37. From this point in time onwards, the severe haemophilia status of my boys meant that I had to place myself in such a position as to be 'on call' for them at all times, and especially when they were to be away from home.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

38. It was again from this point in time onwards that each of my youngest sons began to require increasingly more frequent trips to hospital, often finding themselves being admitted to be kept on 'bed-rest,' which was often for many days at a time – which was likely to cause the relevant joints to become stiff.
39. Both boys were also now treated for their bleeds, which at that time meant their being given a blood product called Cryoprecipitate or 'Cryo' as it was more commonly known. This was a replacement blood clotting factor. Fortunately, both boys were now able to receive treatment specific to the problems they faced, but unfortunately Cryo could then only be administered within a hospital setting, and in the GRO-B Hospital, given in such woefully small amounts as to be relatively ineffective.
40. I feel that I can say this, as by then I had learned a lot about haemophilia and its treatment with Cryo, and have learned more since these initial doses were given. In particular, I had learned how many units would be appropriate to use whilst treating certain types of bleed, and for bleeds into different joints, etc. I knew then, and know now, that the amounts being given to either boy were often inadequate under the circumstances that each of my sons presented to the GRO-B Hospital in GRO-B.
41. In spite of my research, little or no information was available concerning Cryo itself, and I didn't look into it – accepting at the time that it was some sort of treatment that would help them. I looked more at the condition, how haemophilia presented itself, what effect it had on a sufferer (both short and long-term), and how it could be treated with Cryo as opposed to what Cryo was itself, where it came from, who made it, etc. I knew that there could be some side effects associated with its use – staff told me of that, but only minor short-term issues – but not of any lifelong, life-threatening infections.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

42. So far as I was aware, there would not be any serious risks attached to Cryo, only some side effects as mentioned above. I trusted the medical staff and assumed that they knew what was best for my sons.
43. Not long after their diagnosis, our youngest son, then still only a toddler, fell down some stairs and a few days later began passing a lot of blood. I took him to our local hospital [GRO-B] where upon examination a decision was made to admit him 'for observation.' However, despite the diagnosis, and his having been registered in [GRO-B] the clinicians examining him simply didn't seem to believe what I was telling them as to what had happened, what his condition was, and its implications.
44. The following day, I went to the hospital to find that he had slept well overnight and in their eyes was 'fine' and accordingly fit for release. However, shortly before we were due to leave the hospital, he passed more blood, a large amount of blood, and only then did they appear to believe what I had been telling them.
45. The attitude in [GRO-B] was, at times, awful – I felt they simply didn't want to believe me or didn't understand the full implications for my sons of the position they were in because of their haemophilia.
46. At the age of seven, [S2] suffered a very severe ankle bleed and had to be withheld from school for about three weeks. Throughout this time he was unable to walk and I found myself having to carry him around the house all of the time. I rang the hospital [GRO-B] to see if I could acquire some crutches, even if only on a short term loan basis, to assist him and thereby me, as he was getting too heavy for me to carry.
47. The hospital asked that I bring the boy in, which I did, where we were seen by a lady paediatrician, a Dr. [GRO-D] as by now this consultant was treating both boys and we were familiar to her.

- ANONYMOUS -

48. Dr. [GRO-D] decided to examine him, and in so doing took hold of the foot with the swollen ankle and twisted it around, manipulated it through the full range of normal ankle movement, and causing excruciating pain for him in doing so. Having done this, she told me that there was "*nothing wrong with him,*" and that he should have been going to school. There was absolutely no question of our being allowed to have crutches.
49. I was furious, not just with the issue of the crutches but in the manner in which a so-called 'specialist' had ill-treated my son. Manipulating the ankle of a haemophiliac in the way she did was, inappropriate, unnecessary, cruel, painful, and would not have told her anything of his condition other than the fact that the joint 'worked' when forced into doing so.
50. We left the hospital and I immediately rang the [GRO-B] Haemophilia Centre (located at the [GRO-B] where we had been registered) for advice. They instructed me to take the boy to St. Thomas' Hospital in London (which had a dedicated haemophilia centre) and not to return to [GRO-B]. They [GRO-B] then made an appointment for us to be seen at St. Thomas, and we were seen that very afternoon.' From this event onwards, the treatment of both boys was to take place at St. Thomas' Hospital, or in later years at Margate and then at the [GRO-B] Hospital, with liaison with St. Thomas.'
51. It was several weeks before [S2] found himself able to walk again properly and having to endure frequent visits over many weeks to St. Thomas' Hospital for treatment.
52. All of these incidents were occurring in a time before mobile telephones, and the condition of both boys and the resultant need for me to be able to respond as and when necessary, began to control my life. I felt I could not go anywhere unless I was able to be contacted.

ANONYMOUS

- ANONYMOUS -

53. Quite often their school would call to tell me that one or the other of them had a problem and needed to be collected; which I would then do whilst having to arrange care for my other children, by friends, as each call from the school inevitably meant a hurried journey to London for treatment at St. Thomas'. It was a situation which went on for several years. My husband couldn't really help – one of us needed to work, which he did, and when they were poorly, the boys needed their mum.
54. Life for us as parents, and for the boys as children was very difficult – they wanted to go out and play at school as their siblings and other children could, they wanted to play football and so on, but in their case, a fall, no matter how innocuous in appearance, resulted in a trip to hospital.
55. This played on their minds as much as it did on mine, and I can distinctly recall an occasion when our youngest son told me that he wished that he hadn't been born, and life wasn't worth living because he wasn't allowed to do what other boys did and play rough games.
56. I had been instructed by the hospital to take this sort of action, to protect them from bleeds, whether internally or externally, as these could cause long term damage to their joints or muscles. If it was a bang on the head, it was an emergency.
57. As a parent you feel really mean, and it hurt when I found that I had to restrict their activities, however I recall a **Dr. Geoffrey SAVAGE** telling me, at a time when the boys were in their late 'teens, that *'they are in great shape because you took such good care of them,'* so it was something that just had to be done.

- ANONYMOUS -

58. In 1970 S2 fell off of a chair when reaching up to get something. He bit into his cheek upon falling, and bled heavily. Unable to stop the bleeding, as it appeared to us to be an emergency, we took him to the hospital in GRO-B for help. Here they (Accident & Emergency) again appeared to be ignorant of the condition (haemophilia) and how it should have been treated, and were consequently unable to abate his bleeding (this happened at a time before we were under the care of St. Thomas').
59. My son and I were then taken by ambulance to the GRO-B in GRO-B for emergency treatment, this being the only occasion when either of the boys were treated through the haemophilia centre there.
60. Once we became patients of St. Thomas' Hospital, trips became a frequent event, either for treatment in response to bleeds or for the routine examination of each boy in clinic. I can recall a **Professor Ilsley INGRAM**, then the Director of the Haemophilia Centre at St. Thomas' Hospital telling me in consultation that *"in time, your lives will become easier with the ongoing development of new treatments."* I believe this would have been at sometime around 1972.
61. Professor Ingram told me of a plan where children and other haemophilia patients would become able to be treated at home, and that eventually I would be able to treat each boy, at home, myself - by administering medicines to them by intravenous injection.
62. I told the professor that there was 'no way' in which I would ever have been able to inject anything intravenously into my sons, but he sought to persuade me otherwise, telling me what a difference the advancements would make to each of their lives, and consequently that of family and I.
63. 'Home Treatment' as it was called, was sold to me as a means of 'getting our lives back,' a means of being able to live near normal lives, spend more time with our other children, engage with people socially again, to take holidays, which was sometimes difficult, as we never knew whether one or other of the boys would suddenly need treatment.

64. The new treatment presented itself to me as a considerable breakthrough, but the prospect of my having to inject either of my sons nevertheless filled me with terror, despite Professor Ingram's encouraging insistence that I 'could do it.'
65. Eventually, I was shown how to deliver medication by injection through a syringe. It was either Professor Ingram or Dr. Savage and a haemophilia nurse (a nurse specialist sister) showed me how to do it at St. Thomas' Hospital. There I could practise on the boys, under their supervision, and fortunately both children had 'good veins' making things a little easier for me, so in time we began home treatment. I don't think that the boys were then taught how to do it themselves – there was no need, as I was always there for them when they were children – but they were in time.
66. Up until about 1973, both boys had been treated with nothing but Cryo, in hospital, with no alternatives having ever been offered and my having been unaware of any alternatives that may have existed. There was no possibility of 'home treatment' whilst the boys were using Cryo.
67. It was in about 1973 or 1974, when Professor Ingram was promoting home treatment to me, that both S2 and S3 began using an alternative to Cryo known as Factor VIII. Then, once home treatment with Factor VIII started, we were able to keep a small stock of it at home, for use as and when it was necessary, that being whenever they suffered a bleed.
68. Having been taught how to administer it, I was also shown how to store it, and we kept it in a refrigerator at home. I can't now recall ever having been given any written information other than instructions on use that came with the bottles of Factor VIII, as to how to use or store Factor VIII, all of the instructions had been delivered verbally.
69. For many years on home treatment, I would drive to hospital to collect the stock, usually from a hospital in GRO-B once we had transferred there, then take it home and keep it in the 'fridge. It came as a box which contained bottles.

ANONYMOUS

- ANONYMOUS -

70. Although it had to be kept refrigerated, there was no means of carrying it from the hospital to our home whilst refrigerated, so it came out of a 'fridge at the hospital, was taken home with no refrigeration, and then put back into a 'fridge where it remained until necessary. Whether or not this did anything to the Factor VIII, I do not know, but it certainly wouldn't have allowed for it to become contaminated with any infectious disease(s).

71. I cannot now recall a lot about the Factor VIII we used other than to say that the stock we received had been manufactured by the **ARMOUR** and possibly **BAYER** pharmaceutical companies – I particularly remember this from the labelling and / or the packaging of the boxes or bottles themselves, but cannot recall anything as to its country of origin or place of manufacture.

72. By the time we progressed to home treatment, I was exhausted, continually having to journey to and from London with one or the other of my sons, all without any notice, and sometimes several times per week, week after week. I thought that home treatment with Factor VIII would be life changing for all of us, and so it should have been, but sadly their care turned out to be nothing more than a life sentence, and possibly a death sentence.

73. In 1976, my daughter was due to enter St. Thomas' Hospital in order to have her tonsils removed. The operation was being conducted at this hospital as opposed our local hospital, by way of pre-planned surgery due to her status as a haemophilia carrier. The operation was ^{overseen} conducted by Dr. Savage (St. Thomas' Hospital, Haemophilia Centre), and I had intended to accompany her throughout, but shortly before it was due to take place, our youngest son suffered an injury which prevented my doing so.

GRO-B

74. At this time, we had all been on a family holiday in Wales when **S3** was severely injured in an accident. Although we returned home earlier than a hospital really wanted us to, under the circumstances they agreed that we could. This was so **D** could go into hospital for her tonsillectomy.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

75. My husband had to accompany her, as I had to stay and look after our injured youngest son. We didn't want to postpone her operation as she'd had problems with her tonsils for a while and had been waiting for the operation for an appreciable period. I will address the issue of S3 accident later within this statement.

76. The tonsillectomy was undertaken with consent. Although I wasn't there, my husband would have given his permission for it to take place, but I do not know exactly what he may have agreed to at the time. This operation may have been the source of her having become infected with HcV, as we believe that Factor VIII may have been given to her during the course of this procedure (as a result of her haemophilia carrier status), but I have no information regarding this. She was fourteen when her tonsils were removed.

77. At some time between 1976 and 1980, when she was still in her teens, she had to have a tooth extracted by our dentist at the practise in GRO-B. Whereas the tooth was removed in the dental surgery, prior to the procedure we had sought the advice of the St. Thomas' Hospital Haemophilia Centre in light of her being a haemophilia carrier and had been advised that she could be given some of the Factor VIII we held in our 'fridge as home treatment stock for our sons.

78. It would have been Dr. Savage who advised us on this, and would have told us how much Factor VIII she should be given, something which was to take place prior to the extraction. I had no qualms at the time of giving this to her, it seemed a sensible step to take, so I gave her some of the boys Factor VIII as instructed.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

79. My daughter had never shown any outward signs of haemophilia – she was a carrier but no more. There were no symptoms of anything untoward prior to her tonsillectomy, and nothing between that and her tooth extraction. From then on, until 2004 there had been nothing to suggest any problem had arisen, but either during the tonsillectomy or possibly as a result of the Factor VIII I administered to her prior to the dental extraction, she had been infected with Hepatitis C.
80. She has never done or received anything else, at any time during her life, that would account for her having been infected with HcV, in particular no other blood products, or blood transfusions. This was the only occasion when I, or anybody else that I am aware of, gave her any Factor VIII either before, during or immediately after her tonsillectomy or as mentioned prior to having a tooth out.
81. At some time in 2004 – 2005, over twenty years later, our daughter sought medical help having been suffering from progressively worsening fatigue. It was something which she had suffered from over the years leading up until this point, and a condition which had become more and more impactive as the years had passed.
82. D had given birth to five children, under the care of various hospitals, but at no time, despite blood tests having been conducted, had HcV been diagnosed, and despite her complaining to a G.P. of 'tiredness' which simply got worse as time progressed, no one had enquired as to 'why' she may have found herself feeling so lethargic all of the time.
83. I can only think that a good number of opportunities to diagnose HcV were missed as time progressed and her condition simply worsened - and that her condition passed untreated. She was finally diagnosed with HcV in 2004 – 2005, and treated for it.

- ANONYMOUS -

84. Sometime after the boys had been placed on home treatment, and we were dealing with this effectively, their treatment was transferred from the St. Thomas' Hospital Haemophilia Centre to **GRO-B** hospital in Margate, Kent where they were placed under the care of a **Dr. Mark WINTER**. I believe that the transfer had nothing to do with their care delivery, the change was cost driven as a result of the way NHS services are funded.
85. However, although our youngest sons then became patients of the hospital in Margate, certain aspects of their overall care remained the responsibility of St. Thomas' and in particular it was to St. Thomas' that they were referred should any surgery have been found necessary.
86. It was whilst being seen at Margate that Dr. Winter asked if he could take some blood from both boys for testing. These were for what he referred to at the time as being "*special tests*," but we had no idea what he meant by that - I didn't ask and we weren't told. However we would have consented to the testing as it had been put to us in a very 'matter of fact way,' giving no cause for concern, and I trusted Dr. Winter as their doctor. They were, by then, quite used to having blood tests.
87. I do not know if, when asking for the blood samples, the doctor had suspected the outcome of their inspection, as he made it sound as if it was simply a test that was being applied to all haemophilia patients as a matter of routine. I did not suspect, and had no cause to believe, that it was a test being conducted to determine whether or not my sons had HIV. In those days, very little was known of HIV other than it could go on to become AIDS, and that meant death.
88. We were told that the results of this 'special test' would be available in about a week. We waited, and I then received a telephone call from Dr. Winter, the content of which left me stunned – both of my younger sons had been found to have the human immunodeficiency virus, HIV (which at that time was referred to as HTLV3).

ANONYMOUS

- ANONYMOUS -

89. I was in such a state of shock when he told me that all I could do was thank the doctor for his call and for having let us know. I really didn't appreciate the full implications of what I had been told, but understood that it was extremely serious. At the time, S2 was just seventeen years old and S3 a mere fifteen.

90. Looking back, contacting me by 'phone wasn't really the way in which news of this nature should have been delivered. In my view it should have been given in a face-to-face consultation. In that way we would at least have been able to enquire more about the diagnosis, and more importantly what it would mean for the boys.

91. We all held Dr. Winter in the highest regard, and felt that we could really trust him. If either boy had anything wrong with them, they would go to see Dr. Winter as opposed to their own G.P. as they both liked, respected and trusted him.

92. Having been told of their HIV status, I decided not to tell either son until such time as I felt it would be necessary, and decided that I'd do that once they started dating girls. I felt that they had both suffered enough with their haemophilia, and that to have to tell them that they additionally had HIV would be a step too far.

93. I cannot now recall exactly how I became aware that they had also both contracted HcV, but it was some time later, in about 1990 when this diagnosis had been made and I was told – as by then they were both adults. Whenever this happened, it was of little or no consequence as by then HIV had taken precedence and was what they and I, had been compelled to concentrate on.

94. In addition, S3 had also been found to have HbV, but this had been diagnosed much earlier, prior to the HcV diagnosis and came about when he was only about nine years of age. He had become jaundiced and lethargic which meant that he had needed to take a lot more time off of school, over and above his haemophilia related absences.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

95. Around this time, having been found to have HbV, he was often tired and on one occasion, whilst on holiday, was found to have insufficient energy even to walk, and accordingly had to be carried everywhere. It was a situation he passed off very calmly as, "*oh, it's my hepatitis again,*" but no one had ever explained to us what hepatitis was or how it may impact upon him, or us, and no treatment had been given – at the time, it was simply something he and we had to 'get on with.'

96. Returning to 1976 and our family holiday to Wales which I have mentioned previously, I should add that it took place in August of that year. We were in the GRO-B when S3 then just eight years of age had an accident in which he suffered internal injuries including a ruptured spleen. As a severe haemophiliac he bled heavily, internally, and was in a potentially life-threatening position.

97. Initially he was taken to a hospital in GRO-B although I had requested that the doctor present in the ambulance take him to the hospital in Cardiff as I knew that they had a haemophilia centre. However, the doctor said that he was not bleeding and didn't appear to understand that he would have been bleeding internally as well as having a visibly broken arm.

98. The ambulance doctor insisted that we were taken to GRO-B where the hospital treatment was appalling – they didn't understand that his bleeding was both internal and significant. They put a plaster on his broken arm, but otherwise just left him on a couch for well over two hours. Every now and then, someone would come and take his blood pressure, which was dropping rapidly and I could see that his abdomen was swelling.

99. Leaving us in the hospital, my husband drove back to the holiday home we had been staying in, collected some of the Factor VIII we had brought with us, and took it back to the hospital for us to then treat our son. Such was our concern for his health and the gravity of the situation that my husband had even asked for a police escort, only to be refused.

- ANONYMOUS -

100. Once we'd got the Factor VIII, a hospital doctor tried to inject some into him, but was unable to do it, so I did, with our son just lying there in front of us, bleeding internally, his abdomen swelling more and more as he did so – the doctors simply left him, and us, to it.

101. Having been in the hospital for about three hours, we were told that our boy would have to be transferred to another hospital. By this time he had almost lost consciousness, no doubt as a result of the severity of his injuries and resultant blood loss. He was taken by ambulance to Swansea and the Morriston Hospital. The ambulance service had asked that he be accompanied by a nurse whilst 'in transit,' but the first nurse asked had refused to travel with him, so a doctor went as the escort instead. By this time our son had lost consciousness.

GRO-B

GRO-B

102. The difference between the hospitals in Swansea and Cardiff was evident from the outset. Upon our arrival, accident and emergency staff were waiting and actually ran out to the ambulance. They took S3 straight off for a blood transfusion, explaining that they would need to get his blood levels 'up' before they could do anything else, but that he would need surgery as well as the blood. They also had to have platelets flown in from the hospital in Cardiff.

103. He was found to be that poorly that doctors in the Morriston warned us that he may not survive the night, and took him into surgery from which we were excluded – I had wanted to go into theatre with him, but wasn't allowed to do so. In my mind, I felt that he wasn't going to make it, it was an extremely trying time for us all.

104. However, the surgery he underwent was successful and the doctor treating him emerged to tell us that he had suffered a ruptured spleen, a broken arm and also had some head and hip injuries. We were told that he was not to be allowed to move at all. I was shocked to see him as he looked awful – very pale, with tubes going into him. He was put into a single room where he had to remain as an inpatient for many weeks, a worrying period throughout which he remained extremely weak.

ANONYMOUS

- ANONYMOUS -

105. During his time as an inpatient of the Morriston Hospital, he was given what I believed to be the maximum permissible amount of Factor VIII daily, for weeks, as a means of addressing his clotting issues as a severe haemophiliac.

106. He should have remained in hospital for a little longer than he did, but as a family we needed to return home as our daughter had been going into St. Thomas' Hospital for the tonsillectomy I have mentioned previously. The medical authorities in Swansea were apprehensive, but nevertheless let us take him from their care provided we kept in touch with St. Thomas.'

107. We then drove home from Swansea. The journey proved to be a rather harrowing event as with each and every bump in the road, and no matter how carefully we drove, we were worried that further internal bleeding could occur or that we could inadvertently recommence bleeding which had been successfully treated. In any event, we got him home.

108. Whilst an inpatient of the Morriston Hospital, and convalescing thereafter, a period of just a few weeks, our son lost about a stone and a half in weight before he began to strengthen again.

109. A few weeks after the two boys had been diagnosed as having HIV, I was invited to attend St. Thomas' Hospital where they were going to be making a television programme about haemophiliac patients who had become infected with HIV. I went, but do not know if anything was actually filmed that evening, or ever actually broadcast.

110. Whilst attending the television programme meeting, I met with Dr. Savage who asked how the boys were, and in particular how they had 'taken the news' that they had HIV. Although officially we were under Margate Hospital, St. Thomas' Hospital held an overview of their treatment and must therefore have shared information, I was not concerned how Dr. Savage had learned of their HIV diagnosis.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

111. Dr. Savage was concerned that I hadn't by then told either of the boys that they had HIV. He advised me that I should do so, and do so as soon as was practicable. It was a conversation which caused me a great deal of anguish, and I worried about it all the way home, wondering what I could or should tell them, how to tell them and when to tell them. They were not conversations I wanted to have and all the way home I felt sick with the thought of my having to deliver such awful news.

112. Both of the boys had been out for the evening and I returned home before them. The youngest came in first and asked me how I had got on at St. Thomas'? It was an opportunity which I seized, and told him that someone was trying to put a television programme together regarding haemophiliacs who had contracted HIV. I found it a dreadful thing to have to do, but I took the opportunity of telling him that both he and his brother had tested positive for HIV and each had the virus.

113. For a minute or two he remained quiet, taking in what I had said, and then went off to his bedroom without any further conversation. When his brother S2 came in, he too asked how I had got on, and in the same manner I told him as well. He went silent, then also went straight off to bed. Neither boy appeared to want to talk about it.

114. Neither boy spoke to me about it, for a considerable period of time, and it wasn't until my youngest had commenced a college course that the issue came up. At college, a boy who knew that S3 had haemophilia had asked if he also had AIDS?

115. That evening at home, the situation with him was awful – he poured his heart out to me revealing all of his inner most feelings, his worries and concerns he would never be able to have a girlfriend, would never marry, would never have children of his own, never secure a decent job, never get a home, never have a mortgage, etc. he just went on and on about it, sobbing as he did so throughout the night. He was absolutely devastated.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

116. Prior to his having started at college, I attended a consultation he had with Dr. Savage who was aware of our apprehension at the very thought of his going to college. Although he didn't say it to us, I distinctly felt from his non-verbal communication and in particular his facial expressions as we spoke, together with comments such as "*not to worry about college,*" that he didn't believe he'd live long enough to attend.
117. At some point in time, the date of which I no longer recall, I was told that the two boys may have had only about two to three years to live. All thoughts of them dying and of my having to care for them as they did so were truly unbearable. I couldn't bear the thought of losing either or both of them, they were so precious to me.
118. It played on my mind tremendously, the fear and concerns always to the forefront of my thinking, heightening whenever either child was unwell. We were also aware that we had to be careful who we told, as there was so much ignorance around.
119. As a result of a prognosis that each would have 'seriously reduced lives,' we didn't seek to 'push them' at school or college, or encourage them to be careful with finances, as what was the point in our doing so? I wanted the boys to enjoy, such as they could, that which they had left to them, without placing them under any additional pressures.
120. Our youngest son had an unusually large big toe which he frequently 'bumped into' things, and as a severe haemophiliac it meant that he would bleed into the joint which spread into the foot and was extremely painful. When he was about fifteen years old, he went into St. Thomas' Hospital for surgery to correct this, through an orthopaedic procedure in which it was shortened, straightened, and a screw was inserted.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

121. He was an inpatient of St. Thomas' when this took place and here I found that he had been allocated a room at the very end and in a corner of a ward of other patients, and that a bucket had been placed at the end of his bed. The bucket had been placed there so that any cutlery or other materials he may use could be put into it, to be dealt with differently to any other patients.

122. He felt dreadful about this, as he had been both isolated and singled out for special treatment. Having been placed in a corner furthest away from the entrance and other patients, and 'marked' as being different through use of the bucket infuriated me and upset him, but it is not in my nature to complain, so I didn't and neither did he. Non-verbally, it was a means of saying 'Unclean.'

123. I think that given the same set of circumstances, lots of others would have complained, but we did not. At the time I put it down to an ignorance of his condition amongst staff on the ward, and ill-educated fears of infection where ridiculous steps like these had been taken to prevent it.

124. At this time, there was a great deal of ignorance of his conditions and this resulted in inappropriate reactions. In my opinion, the stigma attached to someone with Haemophilia, Hepatitis, HIV or AIDS continues to this day. It's why some people try to go about their lives whilst keeping their status a secret, and may be the reason why witnesses approach initiatives such as the Infected Blood Inquiry 'anonymously,' and I don't blame them.

125. As an example, on one occasion I took one of my boys to stay with a cousin. She asked me if he had brought his own crockery and cutlery with him, to use whilst there rather than hers.

126. I cannot recall when, but in the early days of this scandal, there was a radio 'phone-in' show on BBC Radio 4 where people who had contracted HIV were being discussed. I rang the programme and mentioned that two of my sons had become infected as a result of their having been given contaminated blood products as an integral part of their treatment for haemophilia.

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

127. A studio guest on the programme, a doctor, speaking very softly in what I thought was some sort of 'an aside' (i.e. a remark to someone sat beside them and not meant for anyone else, let alone broadcast), said "... *Well, that's what she says,*" referring to me. She clearly didn't believe me or that my sons had become infected as they had, by using contaminated blood product as a part of their treatment by the NHS.
128. It made me feel like screaming at her, 'why won't you believe me?' I didn't understand how someone in her position, a doctor commenting on medical matters on a nationally broadcast radio show, didn't appreciate what had taken place, how it had occurred, and its consequences. Ignorance and disbelief seemed to prevail.
129. When our youngest son was just twenty years of age, a lump was discovered in his neck and Dr. Savage wanted to admit him to hospital for a Lymph Node Biopsy. He went in and underwent the procedure, being hospitalised for a couple of days.
130. He returned home extremely angry, extremely annoyed that the NHS had put him through this procedure for no other apparent reason and that the sole outcome was to confirm that 'the lump' was connected to his HIV status – something which they already knew.
131. I found a period of the 1980's leading into the 1990's particularly difficult, in particular as a result of what appeared to me to be the continual showing of a television advertisement concerning AIDS – it had images of a gravestone falling backwards. Each time it appeared I felt as if someone was stabbing me in the heart. There were also a number of celebrities who died as a result of AIDS, with each one being well publicised and each article feeling like a knife going through me.

- ANONYMOUS -

132. There was no escaping it, and I struggled going to the funerals of people I knew, as each and every time I imagined that the funeral of one or the other of my sons would be the next. Both boys were then beginning to suffer from regular illnesses and in my mind, each time they fell ill, I thought that it was the 'beginning of the end' for them.
133. A friend who was aware of the boys health issues, called upon us one day, a day when one of the boys was particularly unwell, and having visited and called in on him to say 'hello,' she commented to me that, *"Oh well, we all have to die sometime."* It was a dreadful thing to say - they shouldn't have been dying and certainly not at such a young age.
134. The situation was such that I began to consciously build up memories of them, even though they were both still alive. Each Christmas, or on the occasion of a birthday, I tried to make the most of the event. I couldn't help but think that one or the other, or even both, wouldn't make the next landmark occasion. It made me think of other things, like 'who would be first?' and filled me with horror thinking of how either I, or the surviving sibling would cope with death.
135. During the course of the 1980's into the 1990's, S2 became increasingly ill, lost weight, experienced almost constant diarrhoea and had a cough that seemed to last forever. One night, having already gone to bed, he reappeared looking very pale and shaking. As a result of his coughing, he had brought up a lot of fresh blood. For anyone this can be serious, but for someone with severe haemophilia it was very serious.
136. I administered some Factor VIII to him from the stock we held at home for occasions such as these and then took him by car to the GRO-B Hospital in GRO-B. Such was his condition that we had decided not to wait for an ambulance but to take him to our haemophilia centre in GRO-B as I felt that any delay in securing medical help could have proven fatal, even then, I didn't know if I could get him to the hospital in time.

137. The drive to the hospital was a very scary experience as he was so weak and at one point slumped down in the car. I truly believed that he may have passed away. However, he survived the journey and was admitted to the GRO-B Hospital where he received a lot of Factor VIII, as an inpatient for two to three days.

138. Here he was treated by Dr. Winter again, and eventually recovered. The centre had been moved from Margate to the GRO-B so under Dr. Winter the boys were under the care of this hospital and it was they who acted in liaison with St. Thomas' in London where their haemophilia treatment had commenced.

139. I do not remember exactly when, but at some point in time the clinicians responsible for the care of S2 began treating his HIV with Azidothymidine or 'AZT' as it is more commonly known. This is an anti-retroviral medicine from which he experienced very unpleasant side effects such as nausea and just feeling very ill, but he persisted with it, and eventually it helped.

140. In 1998 his T-Cell or CD4 count went down to less than 10. Apparently, CD4 cells are the white blood cells which fight infection and a usual CD4 count would be between 500 and 1500 per millimetre of blood, so he was in an extremely hazardous position. It would appear that his spleen was effectively devouring the platelets, and as a consequence it had to be removed. This was done at St. Thomas' Hospital.

141. Having had the splenectomy he initially appeared to be doing well, but just three days post-op' he was rushed back into theatre having suffered a cardiac arrest and needed urgent additional surgery. Whilst in the operating theatre, the doctors noticed that he also had Cirrhosis of the liver, but that this was not alcohol abuse related but Active Micronodular Cirrhosis, information which I know to be in S2 hospital notes.

ANONYMOUS

- ANONYMOUS -

142. Some years earlier, in 1990 when our youngest boy had been about twenty years old, he was seen in clinic by Dr. Winter who told him that he had been found to have HcV.

143. Nothing much was explained to him at the time, either about the condition or how he may have succumbed to it other than through 'contaminated blood.' There was no written literature about it available to him, and no information as to any means through which it could be treated. I am not aware of his having been referred to any self- help groups or support organisations by the doctor during this consultation.

144. Again the diagnosis was given in a very 'matter of fact' way by Dr. Winter, and it appeared that this was in part because HIV was the major issue facing S3 at that time. We believe that all haemophiliacs had been tested or were then being screened for HcV, and this diagnosis was a result of that process. He was subsequently treated with Interferon as regards the HcV.

145. HIV always appeared as the main concern, and in the 1990's I was encouraged to join a support group for the carers of people with HIV. Although I found it good to make contacts with people going through the same things as myself, I also found it very depressing.

146. So many of the people I met had lost loved ones to HIV and spoke of that, and their experiences. My sons were still alive and I didn't find it helpful as it offered nothing other than to anticipate the impending death of two of my sons.

147. Sadly S2 health continued to decline following the splenectomy and discovery that he had cirrhosis. I recall that a friend invited him to attend a wedding in London, which he insisted on attending despite appearing to be too weak to do so. I actually tried to persuade Dr. Winter to intervene, but he simply told me that, *"He won't listen to me!"*

- ANONYMOUS -

ANONYMOUS

- ANONYMOUS -

148. By now it had also been discovered that one of his lungs had collapsed, but he went to the wedding all the same, where a friend took great care of him, having promised to contact me if he needed to return home early. I was so concerned whilst he was away, that I sat by the 'phone all day, just in case they should call.

149. S2 was now very weak and looked ill to anyone who may have seen him. We actively contemplated his death and discussed funeral plans. He had a good friend who was a pastor who wanted to be alongside him when he passed away. We planned to ask the pastor to officiate at his funeral, whilst we busied ourselves making a list of all of the people we would need to contact in the event of his death.

150. However, about a year later, he married. As a direct result of the medication he was on, he had become much stronger. Dr. Winter was invited to the service and I remember that in his reply to the invitation he commented that only the year before he had been anticipating his funeral.

151. In 2012 both S2 and S3 commenced a course of Interferon treatment for HcV. Although it was administered through Kings College Hospital, London, I believe that it came about as a proposal of the haemophilia centre at the GRO-B Hospital.

152. Interferon is an extremely unpleasant drug with nasty side effects including heavy, persistent flu like symptoms which S2 in particular suffered from. The course of Interferon treatment lasted for some twelve months, but despite the side effects S2 completed the course. However, almost as soon as he had done so, he had to be rushed into Kings College Hospital having suffered a brain aneurysm. Within three days he had additionally developed pneumocystis pneumonia and went into multiple organ failure.

- ANONYMOUS -

153. He had to be placed on a life support machine and after just a few days we were told by his doctors that they did not think he would survive, but he did. These proved to be traumatic weeks for us all, emotionally draining, especially with the constant worry as to whether or not he'd pull through, and what, if any, lasting damage he may have sustained, but he slowly strengthened. It was a roller-coaster of emotions where some days there was hope only for his condition to worsen again.

154. Apparently all of the issues he faced at that time were a direct result of his treatment with Interferon, a drug which had further reduced his immune system beyond the damage already evident from HIV.

155. In 2015, he was found to have cancer on his tongue and had to have a section of it removed. At the same time, he had to endure his neck being cut open to allow for the clinicians treating him to see if his lymph nodes had been affected. Whether or not this was an AIDS related cancer investigation, I do not know.

156. Over the years I have already done a lot of grieving in anticipation of losing one or both of my youngest children, but I am glad to say that they are both still alive albeit they take a variety of medicines to treat their respective conditions.

157. Both boys were treated with Interferon for HcV, and despite the problems experienced by S2 both were cleared of HcV infection as a result. Sadly the infection has left a legacy with S2 having a damaged liver which has to be monitored regularly for any further deterioration.

158. The Interferon treatment given to S3 also saw him suffer adverse side effects, in particular towards the end of the course of treatment when he was very ill, finding difficulty breathing and with it being almost impossible for him to take more than just a few steps. It weakened him so much that eventually he stopped taking it, but fortunately he had taken enough over a protracted period that it had already done its job, and he was 'cleared' of HcV.

159. I can't remember when, but some time ago S2 and S3 each received letters telling them that they had been given blood products from a batch which contained material which had come from a person with vCJD. It had been sent by Dr. Winter and was a very inconsequential text with nothing mentioned other than the fact that they had each been exposed to vCJD - but that there was a minimal risk of anything further occurring as a result.

160. Whilst in her forties, many years after she had been given Factor VIII, our daughter had been suffering from fatigue which worsened to a point of chronic exhaustion. Blood was taken from her for testing and it was discovered that she too had Hepatitis C. She now finds herself unable to work due to fatigue.

161. In an effort to rid herself of HcV she too underwent a course of Interferon treatment, suffered the side effects and completed the course, but unfortunately for her it didn't work. She was subsequently chosen to participate in the trial of another medicine for treating HcV, which proved successful, but I do not now know what this experimental treatment was called.

162. As a result of the HcV she had, and the lengthy period over which it had been present (she last received Factor VIII as a teenager), she has been left with thyroid and skin problems, together with chronic fatigue. In so far as her liver is concerned, I believe that it's 'not too bad' at the present time. She is monitored annually through her local haemophilia centre, because of her being a carrier, but my understanding is that she is no longer monitored for any liver problems.

163. At times, I feel angry that three of my children have had to suffer so much, and that their lives have been so badly affected, and all so needlessly. I find myself feeling guilty, as I placed the contaminated product into their veins, and although I know that they do not blame me, I cannot help but feel this way. It is a very difficult burden to carry. There have been so many 'ups-and-downs' across our lives that I feel as if I have been riding a roller-coaster and all as a result of the government and NHS having provided contaminated blood products which three of my children used.

Consent:

164. When acting on behalf of my sons as their parent, when they were children, I do not feel that I was ever provided with sufficient information enabling me to make informed decisions as regards testing of the boys for either HIV or HcV.

165. As haemophiliacs, once diagnosed, blood tests were being undertaken with such regularity that it became commonplace, just 'one of those things that was done,' and it was not unusual for us to have no idea as to what their blood was being taken for or how it may have been used thereafter.

166. We assumed, as you did in those days, that whatever the doctors were doing, it was being done 'for the best.' Nowadays things would be different and I would question what was being proposed, why it was necessary and what it sought to achieve, but it wasn't in my nature then, and I had no cause to do so.

167. Since their diagnosis, I have received more information as regards HIV, but this is because I wanted to know more and made a point of asking, in particular asking Dr. Savage, but I didn't take the same stance as regards HcV. I am now far better informed than I ever was by the clinicians and could now ask appropriate questions, but that's now sadly too late.

168. As my youngest sons got older, they themselves gained more information about their conditions in their own right. S3 in particular was very open and questioning whilst S2 had a close friend who provided a lot of support to him. I do not know what their approach to issues of consent may be now, but they are now far better informed than ever they were.

169. As regards any trials or research that may have been undertaken, I was never told of any use of the children in any trials or research. I was never asked if their blood could be used for research purposes and was unaware of them being treated on any form of experimental basis.

170. However, S3 has told me that having seen his medical notes for 1984, a record shows that 10ml of blood was taken from him "for research." He would have been 15 / 16 years old at the time, and as I always accompanied him to any clinical appointments, I should have been asked for consent – but I wasn't.

171. As a result, I believe that it is fair to assume that blood was taken from both boys for research purposes without their or my consent (as their parent) – particularly as both were treated by the same people working in the same establishments over the same period of time.

Treatment, Care & Support:

172. Neither boy has been able to secure life insurance, but they have been able to obtain travel insurance. They both have mortgages, but I do not know of any issues they may have experienced in securing them.

173. In my own regard, whereas my status as a haemophilia carrier is to all intents and purposes hidden, a few years ago I required the extraction of a few teeth, and the dentist would not proceed to make the removals until such time as I was able to present a letter from the GRO-B Hospital, Haemophilia Centre stating that it was safe for them to proceed, as my clotting factor levels had considerably increased with age.

174. Additionally, in 2018 I had to attend the GRO-B Hospital for an endoscopy and was seen as the last patient on the list for that day and I do not think that I necessarily should have been; and a nurse asked me if I had previously received any blood transfusions and also something regarding vCJD, none of which was relevant as I posed no threat of infection to anyone. The clinicians would not perform this exploration until such time as they had checked for themselves with the haemophilia centre that it was safe for them to do so.

175. My husband and I have never been offered any form of professional support by way of counselling. Looking back, I do not think that this would have been helpful in my case, even if it had been offered, as where I worked (providing a counselling service), there was always someone I, or we could have turned to, but I think that in other cases it should have been put in place by the N.H.S., or to prevent concerns of bias, by an independent provider (but funded by the NHS).

176. I think that counselling could and perhaps should have been provided through the various trusts and schemes that have been established to assist those whose lives have been impacted upon. Had this been done, it would also have needed to be 'fee-free' and unrestricted as to the number of counselling sessions that were necessary, as is quite often the case with other referrals for counselling services.

177. The Infected Blood Inquiry may be interested to note that Dr. Winter GRO-B
GRO-B Hospital / Margate Hospital) had worked alongside a male nurse (someone called Martin) who was made available for people to talk to, for support, but he may not have been a trained counsellor.

178. In the early 1990's I retrained and then established a professional counselling centre. I carried on counselling until I was seventy-six years of age and whilst so doing, but quite independently of my work, became involved with an HIV training course. This saw me giving talks to doctors social workers and other health and care professionals, telling them what it was like to live with or care for someone with HIV.

179. At one time one of my sons also delivered these talks, but sadly had to stop as the amount of time he was taking off work to do so became prohibitive. I replaced him until this input was no longer required. It would have been extremely helpful, looking back, to have had someone to turn to, or a service in place, where the issues you were facing and the very real concerns you experienced were known and understood and you could hear from people who could offer tangible assistance.

Financial Assistance:

180. Normally, once your children start going to school as a mother you can return to work, but this was not the case for me as I had to be available at any time to respond to problems which may have arisen, and if necessary take the boys to hospital.

181. This meant that I didn't have any personal income. I had been employed as a **GRO-B** secretary prior to my marriage and then worked in an estate agency until the children came along. Obviously it wasn't possible for me to go out to work until such time as both sons were older and didn't need me so much, and so I then trained and went into counselling.

182. With a home to run and four children, my not being able to work caused financial problems for my husband and I, and as a consequence at one point in time he held no fewer than three separate jobs in order to provide for us, and in particular fund the regular car journeys to hospital in London and elsewhere.

183. Neither my husband nor I received any assistance other than for a time through Disability Living Allowance (DLA) and Motability benefit until such time as the boys were old enough to receive these allowances in their own right. For a short time I received the Carers Allowance (before S2 left home), but I had not been told that I qualified for this, and by the time I had, S3 had already left home.

184. Both of our younger sons and daughter have been assisted financially, but to varying degrees – my daughter received some assistance from The Caxton Foundation, but has also been refused payments more than once. The boys have each received various payments, and I am unaware of either of them ever having had an application declined.

Other Issues:

185. When S2 was aged eleven, we had a visit from a local authority (GRO-B County Council) Education Officer (possibly a 'special needs' social worker or an educational welfare officer, or someone with that sort of role) who amongst other things, asked us where we intended sending our children (i.e. the two boys with haemophilia) to school.

186. They had been attending a local primary school, and I responded that I'd be sending them to 'the school across the road,' as it had never crossed my mind to send them anywhere other than to our local 'normal' mainstream school.

187. The Social Worker encouraged us to think about sending them to a 'special school,' and the Lord Mayor Treloar College was recommended to us as somewhere we should consider, but there was no way that we were going to willingly send our children to a boarding school, and certainly not one so far away.

188. My husband and I explored suitable local schools and eventually sent both S2 and S3 to GRO-B School, much closer to home and where the headmistress appeared far more knowledgeable around haemophilia and the issues our sons may encounter than others - she happily accepted them both into her 'mainstream' school for which I am most grateful.

189. I have attended a London hearing of the Infected Blood Inquiry and followed others online. I have found it quite harrowing to listen to the stories which witnesses have told, but at the same time found that I could relate to quite a lot of their accounts. I believe that this inquiry presents itself as a good opportunity for people to share their experiences and for others to have the chance to learn exactly what happened and of its impact.

190. Both of my youngest sons and myself have been members of the 'Tainted Blood' group, something which has proven to be a positive experience.

191. My daughter, as I have said, is unable to work due to fatigue as a result of Hepatitis C. She has five children, one of whom (a son) has Haemophilia A. Our eldest son lives overseas, does not have haemophilia and was uninfected. My son S2 who married in GRO-B has two children, his daughter being a carrier of haemophilia. My son S3 is also married and had three children, one of them (a daughter) being a carrier of haemophilia.

Statement Of Truth

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

Signed:

GRO-B

Dated:

1st February 2020