ANONYMOUS

Witness Name: GRO-B

Statement No. WITN0327001

Exhibits: WITN0327002 – WITN0327008

Dated: 3rd / January /202[illegible] 2 Joc.

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 7th December, 2018.

I, GRO-B will say as follows:-

Section 1 - Introduction

1. My full name is GRO-B and I was born on GRO-B GRO-B 1954 in the Republic of Ireland as one of ten children in my family. I now live with my wife in the West Midlands, at an address that is known to the Infected Blood Inquiry.

2. I was born with the blood condition haemophilia – I only produce about 26% of the blood Factor IX which I require, and as such am considered to have mild haemophilia or what is known as Haemophilia B or Christmas Disease.

3. Having said that I was born in Ireland, I should now state that I came to the United Kingdom as a child, and have only ever been treated as regards my haemophilia here, by the National Health Service (NHS).

4. Having been born in Dublin, Ireland, I moved to a relative's home in Birmingham, with my father and other siblings when I was twelve years old. I had four brothers and five sisters, sadly two of my siblings have since passed away.

5. Although we didn't appreciate it when I was born, but have subsequently found out, I was a hereditary haemophiliac with a history of haemophilia in the family, my mother having been a carrier of the condition. An uncle (on my mother's side), a cousin and one of my sister's sons (who lives in Canada) all have haemophilia.

6. I say that we didn't appreciate it at the time, apparently my mother had been advised not to have too many children because of her condition, but doesn't seem to have heeded that advice. Sadly, she passed away when I was only four years old, following a bleed she had in one of her legs. Her death, and his pursuit of work, brought my father and I with some of the family to the U.K.

7. My mother actually gave birth seven or eight times, despite having been advised against it due to her failing health, but she was wholly unaware that she was carrying the rare blood disease which she passed on to me.

8. I left school at sixteen, but it was at school where my problems first became apparent as I suffered a serious swelling in my throat, caused by a fishbone having got stuck, and had to be treated at the Queen Elizabeth Hospital in Birmingham.

9. Having left school, I went to work on a building site in Birmingham and for McAlpine on a tunnelling project. I started as a tea boy and worked my way up. Following that, I have held a variety of other jobs, many in manufacturing including roles in a rubber factory, a dry-cleaners and at GKN, a major engineering company at the time. I usually worked as a machine operator, which like the work on the sites and building the tunnel were heavy, manual labouring jobs – not ideal for someone with haemophilia, but my condition was 'mild,' so I was able to work in these roles and despite problems, learned to work around it, or with it.

10. In 2017 I retired from work. At the time I was engaged as a maintenance man working in GRO-B

11. I am a married man, having met my wife GRO-B when I was twenty-three years old, and we have two children, a son and a daughter, twins who are now adults (currently 27 years of age).

12. I intend to speak of my infection with Hepatitis C (also referred to as Hep' C and / or HcV) which happened as a direct result of my having been given whole blood and blood products as a means of treating my haemophilic bleeding, and in particular I will address the nature of my illness (Hep' C), how this illness has affected me, the treatment I have received as a result of having HcV and the impact Hepatitis C infection has had on my life and that of my family.

Section 2 - How Infected

13. In spite of the family background, I only found out that I had Haemophilia B when I was around fourteen years of age. During the course of a school lunch, a fish bone became lodged in my throat and in some manner or form bruised or cut my throat's lining. It quickly became swollen, and the swelling wouldn't abate, so I was taken to the Queen Elizabeth Hospital in Birmingham who intervened and found, upon running some tests, that I had Christmas Disease.

14. I hadn't known this before coming to the U.K., as it hadn't been diagnosed and I'd given no grounds for the likelihood of my having any issue such as this simply hadn't arisen before. I don't believe that my father was any the wiser either, or he would have explained things to me – which he hadn't done. It seemed to come as much of a shock to him as it was for me.

15. I do not now recall how I was treated when this happened, or with what, if anything, but suspect that it would have been with Factor IX.

16. Having said that I'd given no cause for my condition to have been explored, until the fishbone incident, I did nevertheless show symptoms – as a young child whenever I played football, or other sports, I found that I would bruise easily, far more readily than my peers, and could suffer swollen joints.

17. Following the fishbone incident, and resultant diagnosis, I became a patient of the Queen Elizabeth Hospital where whenever I suffered a bleed or swelling, they'd treat me with Factor IX – eventually I had to stop playing football and ding other things like that, all of which I enjoyed doing, as most boys do, for fear of causing permanent injury.

18. I have now been attending the Queen Elizabeth Hospital in Birmingham for over 50 years. It's the only place at which I've been treated, although I have been cared for by a number of doctors over the years, notably including a Dr Pritchard (who treated me in the children's hospital), Dr Wilde (who then treated me for many years) and most recently Dr Lester. Once they came into being, I was treated through the dedicated Haemophilia Centre at the hospital.

19. As a schoolboy, I missed a lot of schooling through my bruising, swelling and a lack of mobility as a result meaning that I couldn't actually get to school. If I had to be treated at hospital, I would usually be kept in for anything between 24 and 48 hours until such time as any swelling had been reduced.

20. Having said that, I cannot 'blame' Haemophilia B for all f my absences or for not having achieved to my fullest potential at school, I was something of a feral child and my dad, having a number of children to provide for, was a hard-working man who had exerted little or no control over me. It wasn't a care issue, he simply had too much on his plate, in many respects my aunt stood in for him or he relied upon my elder sisters to help.

21. As a consequence, it was often my aunt or one of my sisters who'd accompany me to hospital, and they weren't so much interested in what was happening, more 'when' they could get me out.

22. From my late teens or in my early twenties, I received Factor IX as the preferred means of treating any bleed – before this I was given whole blood and possibly some Factor IX, but I'm now none too sure when that became the first choice treatment at the hospital. I would go whenever I had a bleed that needed treatment, and also for bi-annual check-ups which would consist of blood tests and a physical examination.

23. I had been relatively injury free in my early years, then in my teens the accidents started to occur, and in my mid' to late twenties I suffered a series of injuries, many work-related, and which included my having fallen onto a piece of glass sustaining cuts, and having broken an ankle – all treated with Factor IX. In my late thirties and early forties, I also experienced a lot of spontaneous nose bleeds, often daily nose bleeds.

24. Aged about thirty-five, I experienced problems with the veins in my legs which kept swelling up, and had to have an operation to address it. On this occasion, to facilitate the surgery I required, I was given either a blood transfusion or Factor IX in advance of the operation being conducted. For reasons which I will explain later within this statement (please see paragraph 39), I cannot now recall which.

25. For the same reason, I cannot now remember when I stopped being given blood and went over to being treated solely with Factor IX.

26. I have never had to self-administer any blood product such as Factor IX as I have never been on 'home treatment,' all of my care having taken place in hospital. As a mild haemophiliac I am fortunate not to have had to have a great deal of treatment and as an average would say that I only needed treatment with Factor IX once every two years of so (but sometimes I could go longer without treatment, at other times I'd be treated more often then go without for a longer period, it varies).

27. In the early 1990's, I received a letter which told me that I had been given blood or blood products which had come from a source known to have been contaminate, and was called in for a blood test. Dr Wilde dealt with this and tested my blood for both the Human Immunodeficiency Virus (HIV) and Hepatitis C. I was found not to have HIV but I did have Hep' C.

Section 3 - Other Infections

28. I do not believe that I have been infected with any diseases other than HcV, although I was most probably also exposed to HIV or there would have been no cause for me to be tested for the same.

29. Some years later, in September 2004, I received a further letter telling me that I may have been exposed to Variant Creutzfeldt–Jakob disease or vCJD, again as a result of blood or a blood product I had been given which would have had to have come from a known contaminated source.

30. Unlike HIV and HcV, there was, and remains, no test for vCJD, so this news, which offered no comfort or treatment path (as apparently there isn't one), came as a complete shock and has remained aa worry for my wife and I ever since.

Section 4 - Consent

31. I do not believe that I have been tested for anything against my will or without my prior knowledge and consent.

32. In the 1970's and 1980's, I held no concerns as to the integrity of the blood or blood products I was being given to address my bleeds. In part, this was because it had never been explained to me that there was any risk associated with the use of whole blood or Factor IX, so not knowing of any risk I had no cause for concern. With the benefit of hindsight, as soon as any form of risk were known, I believe that I should have been told.

Section 5 - Impact

33. Prior to my Hepatitis C diagnosis, I had noticed that I was often abnormally tired and lethargic, but for no apparent reason. Once Hep' C had been diagnosed, and I'd learned a little about it, I realised why I had been feeling so run down all of the time, it was a side effect of the condition.

34. I found the whole situation very stressful which in its own way added to my problems as it made me anxious. I worried about talking to people about my situation or even mentioning that I had HcV. I worried that if I told anyone about it, they would keep away from me, from us, and we'd become isolated. As a result, I kept my own counsel and never discussed it openly as the stigma associated with the condition at that time was awful.

35. At the time I had been working for Lucas, and I can distinctly recall my having been quite embarrassed at having what was being described as the disease of 'low-lifes,' and I was really worried that I may have to declare or explain my health status to others, but I had to tell my employers.

36. Lucas were very accommodating and understanding, which came as a great relief. I also discussed it with my wife's parents, which was difficult as they were concerned for their daughter, but again they were very supportive. The main issue was that as I had haemophilia, which was known, and haemophilia had been associated with HIV, some people jumped to conclusions, considered that I had HIV or would have been likely to think that if they knew, so I became secretive about my health and the symptoms (of HcV) I was experiencing.

37. My concerns as to the stigma associated with the condition, and the association of people with haemophilia to those with HIV / AIDS, primarily driven by fears, concerns and a lack of proper information across the public persist to this day. Although I am now clear of HcV, I do not mention it to anyone as I worry that they will make assumptions about me that aren't correct and treat my wife and I differently as a result.

38. I was so concerned of the stigma associated with my condition, that it actively prevented me from pursuing a number of job opportunities where I new or found out that I'd require a medical or would have to provide medical information in order to secure the position I would otherwise have sought. I deliberately avoided anything which would have revealed my condition, and in particular any disclosure of my having Hepatitis C.

39. However, my having Hepatitis C did not change our family life or the way we went about doing things. We chose not to take any further precautionary measures as a result of my having Hep' C, but it did affect us when trying to secure travel insurance for foreign holidays.

40. This situation persisted even once I had been declared 'clear' of the infection. I consulted a social worker, someone who was based in the centre at the hospital, for help with this issue, caused as I was compelled to declare my having had HcV even though I was no longer infected.

41. Once on a dedicated treatment regime for Hepatitis C, I went on holiday and as such had to take the medication, which I was self-administering, with me. In order to be able to go, I had to get a letter from the hospital to support my need for the medication in order to secure the permission necessary to carry it aboard a plane. It was embarrassing.

42. Fortunately, there is currently no evidence to suggest that Hepatitis C infection has caused any cirrhosis in my liver or hepatic cancer although its function has been impaired.

43. Last year (2020), I suffered two strokes from which I am only now slowly recovering but with a determination to get better. As a direct result, I now have some cognitive disorder which impacts upon my ability to concentrate for any length of time, to recall particular events, or to be able to place them in the correct time order. This has meant that I have had to rely upon my wife, GRO-B for assistance including her having helped me with the drafting of this statement.

44. I also have some cholesterol in my neck, for which I require blood thinning medication, but as a haemophilia patient, this is a difficult issue for the clinicians to address and as such the doctors dealing with the stroke and blood thinning necessity have had to work in close contact with the haemophilia centre – everything I do or take has to be undertaken with one eye on my vulnerability due to Christmas Disease.

Section 6 - Treatment / Care / Support

45. Soon after I had been diagnosed as having contracted Hepatitis C, I was told that there had been some adverse impact upon my liver function. As a consequence, I was put onto an HcV treatment programme fairly quickly post-diagnosis, but cant now specifically remember what I was given, although I believe it may well have been Interferon.

46. In order to receive this treatment, I was taught how to self-administer, something I'd never had to do as regards my haemophilia, and which I then did three times a day for a period of about six months. Dr Wilde at the Queen Elizabeth Hospital Haemophilia Centre put me onto this course ad he monitored its progress. I would travel to see Dr Wilde about once a month for a check-up, which usually consisted of a blood test and questions – how was I getting on, what side effects was I experiencing, that sort of thing.

47. At the end of the course of treatment I was found to be clear of the virus, I no longer had Hepatitis C.

48. I wasn't offered any form of psychological support as regards my having been infected with HcV, or to assist during the course of its treatment. Looking back, I think that this would have proven very helpful had it been offered, not only for me but for my wife as well, not least because we had nowhere to turn to, we knew no one who was going through the same thing.

49. Had there been a self-help group or other organisation to whom we could have turned with questions I feel that it would have helped us greatly, but there wasn't – at least none were ever presented to us.

50. This is in stark contrast to the situation which exists and the support I have enjoyed since having suffered the strokes – we were very quickly out in touch with a number of organisations who were able to help us and whose assistance, even just to answer a question or two, has proven invaluable.

51. Looking back, I wish that my wife and I had been given more information during the course of our clinical interactions – what was the disease, how had I come by it, what would it do, how could it be treated, what was the long-term impact, what else could happen, why was that test necessary, what are you looking for? There are lots of questions which it would have proven very useful to have been given the answers to, up front, at the check-up. Even now, I happily turn up and give blood 'for testing,' but don't really know what it is being tested for, why or how the outcome may affect my future treatment. Everything should be made a lot clearer for patients from the outset.

Section 7 - Financial Assistance

52. I am currently in receipt of financial support from the England Infected Blood Support Scheme (EIBSS) having previously been financially assisted by The Skipton Fund. I had initially applied to 'Skipton' and my case was passed on by them to EIBSS when they assumed responsibility for the financial support of folks like myself.

53. I recall that the application process had passed relatively smoothly, and assistance was secured without any problems. I received two lump sum payments from The Skipton Fund, and am now in receipt of a monthly payment through the EIBSS. My monthly payments (under 'Skipton') had been about £350- per month, now they are £2,353.00 p.m.

54. In May 2004, I received a letter from Andersen Eden Solicitors informing me that in order to participate in a Class Action, I was advised to secure copies of my medical records – presumably to show from NHS records that the NHS had given me blood and / or blood products which being contaminated had led to my contracting Hepatitis C.

55. As a result, in June 2004 I requested copies of my medical record from the Queen Elizabeth Hospital. Unfortunately, I received no records as a result of this application as I was told that my record had *"disappeared or been lost."*

56. As a consequence, my participation in the proposed litigation case went no further, with the solicitors declining to represent me in the absence of medical records.

57. I also paid £15- to what I believe to have been the United Kingdom Haemophilia Centre Directors Organisation (or UKHCDO) for copies of any records they may held in my regard, and as I explain later within this statement (please see Section 8), the UKHCDO initially provided some records, and then some fifteen years later produced others – too late for use as regards the litigation, the moment for which had by then (2019) long since passed.

Section 8 - Other Issues

58. In order to assist the Infected Blood Inquiry with their understanding of my position, I now provide copies of a number of documents I have retained, as documentary exhibits.

Exhibit WITN0327001

59. A copy of a letter, dated 27th May, 2004 from Lynne Wilson of Anderson Eden Solicitors to myself, encouraging me to secure copies of any relevant documents and in particular medical records (as regards my treatment, as someone with Christmas Disease, by the NHS with blood and / or blood derived products) so that I may participate in litigation (a group action being taken to seek compensation for persons like myself who had been infected).

60. As you will have read earlier within this statement, efforts made to secure medical information in support of any claim had proven unsuccessful, the hospital having apparently 'lost' my file and within it any relevant records. I undertook these enquiries in my own time and at my own expense, and found it a lengthy, often confusing and frustrating process which allowed me to understand exactly why so many people who had become infected as I had, gave up.

Exhibit WITN0327002

61. A copy of a letter, dated 10th December, 2004 from Alexandra L. Foote of Lieff, Cabraser, Heimann & Bernstein LLP based in California, USA to myself, copied to Anderson Eden Sol's., showing the American lawyers as having declined to represent me in litigation (by way of a class action being undertaken in the USA). This was as a direct result of my not having been able to substantiate a claim for compensation for HcV infection arising from my use of blood and / or blood derived products in the absence of my medical records.

Exhibit WITN0327003

62. This is a copy of a letter I sent on 2nd July, 2004 – between the first and second letters above – from me to Lynne Wilson updating her on my efforts to secure my medical records from the Queen Elizabeth Hospital (Haemophilia Unit), Birmingham. Within the letter I noted that Dr J. T. Wilde had told me that my notes had apparently 'disappeared.'

Exhibit WITN0327004

63. In the absence of any relevant medical notes from the Queen Elizabeth Hospital, I contacted the National Haemophilia Database (with whom I had been registered for many years) operated by the UKHCDO (United Kingdom Haemophilia Centre Directors Organisation). In response to my request, they sent me five pages of information which appeared to show my having been registered with the database from 1974 and having been assessed as having the ability to produce only 26% Factor IX.

64. This meant that I had a form of haemophilia more commonly referred to as Haemophilia 'B' or Christmas Disease and that my condition would be considered by clinicians treating me as being 'mild.'

65. The record revealed that I had been treated as follows: -

1976 - Nothing shown, an entry marked 'error' appears
1978 - Tranexamic Acid
1980 - BPL FIX (I believe this to have been Factor Nine as provided by the Blood Products Laboratory)
1981 - BPL FIX
1982 - BPL FIX
1983 - BPL FIX
1984 - BPL FIX
1985 - BPL FIX
1987 - BPL FIX
1988 - BPL FIX
1990 - BPL FIX
1991 - BPL FIX
1992 - BPL FIX
1993 - BPL FIX
1994 - Alphanine
1995 - Replenine
1996 - Replenine

1999	-	Replenine
2000	-	Replenine
2001	-	Replenine

66. In my opinion the record provided was incomplete – it showed only years and not full dates, and only noted the use of blood products and not whole blood, but it was all which the UKHCDO apparently had upon their database in 2004 when the record had been sought – each page is dated 09/07/2004 which I believe to have been the date upon which it had been printed from the record held on their computer system.

Exhibit WITN0327005

67. Many years later, and after I had been unable to participate in any form of litigation as my records were missing and / or incomplete, I received a letter from the UKHCDO, National Haemophilia Database (NHD). This was dated 15th October 2019 and came from a Professor Charles R. M. Hay, the NHD Director.

68. His letter referred to my earlier (2004) request for information held on the database and informed me that when the information I had previously been given had been sourced (i.e. Exhibit WITN0327004), an incorrect assumption had been made that the computer-based record had been a complete record, as I had thought but had been unable to challenge.

69. Professor Hay stated that as a result of an inspection of material held within their database archive, further information had been uncovered, documentary records submitted to the database during the course of the 1970's to 1990's (inclusive) by haemophilia centres, but which had not been entered onto the computer. He did not say 'why?' they had not been placed upon the computer system, merely that the database had been held in Oxford until such time as reporting to the database on paper forms had been phased out in 2000.

70. I received ten pages of information together with an apology from Professor Hay for "any distress or difficulties this may have caused." He also explained why two pages of text appeared in redacted form – as details of other persons appeared in addition to myself.

Exhibit W0327006

71. These are the ten pages of information provided with the above letter (Exhibit WITN0327005). Only two pages were handwritten or had been taken from 'paper forms' – each of the others appeared computer generated and very similar in nature to those I had received in 2004.

72. One of the handwritten (on a typed page) pages showed that I had been treated in 1974, as a patient with Christmas Disease, at the Queen Elizabeth Hospital, Birmingham, but it did not say exactly when, why or with what I had been treated just that I had been.

73. The second handwritten (on a typed page) page, an annual return for 1975 extract, again showed me as having been treated in the same place, this time in 1975, but did not say when, why or with what, if anything.

74. The only issue of note which I could take from either form is the fact that a column on each required the person completing it to note as to whether or not I had been jaundiced – a sign that in 1974 / 1975, the clinicians maintaining the NHD in Oxford were concerned for the presence of Hepatitis and its transmission to patients with haemophilia.

75. One of the other forms (which appears to be computer generated), which is marked in its header as being '04 Patient Annual Treatment Record,' replicates the list as had been seen in Exhibit WITN0327004, showing my having been treated as follows: -

1976 - No product shown
1978 - Tranexamic Acid
1980 - FIX (BPL)
1981 - FIX (BPL)
1982 - FIX (BPL)
1983 - FIX (BPL)
1984 - FIX (BPL)
1985 - FIX (BPL)
1987 - FIX (BPL)

1988 - FIX (BPL)
1990 - FIX (BPL)
1991 - FIX (BPL)
1992 - FIX (BPL)
1993 - FIX (BPL)
1994 - Alphanine
1995 - Replenine (BPL)
1996 - Replenine (BPL)
1999 - Replenine (BPL)
2000 - Replenine (BPL)
2001 - Replenine (BPL)
2003 - Replenine (BPL)
2004 - No dose (administered)
2005 - BeneFIX (3,000 units)
2006 - No dose (administered)
2010 - BeneFIX (7,000 units)

76. The record also noted that in 1999, 2000 and 2001 I was a patient on "regular home treatment." This information is incorrect, I wasn't at any time on any form of self-administered home treatment using Factor IX and have only ever been treated following a bleed and in hospital with the sole exception of when I required surgery (as detailed earlier within this statement).

77. One page of these ten, as provided by the UKHCDO NHD is marked in its header, 'Hep C 2018.' This takes the form of a number of coloured text boxes, each containing information with a smaller accompanying text box accompanying each one. The information held herein shows that insofar as Hepatitis C is concerned, I received factor concentrates before 1988 and had received blood components prior to 1992 and had tested positive for the HcV antibody.

78. I have been concerned for the condition of my liver for some years now, especially as following initial Hep' C diagnosis, and then my having received treatment for Hep' C, I have had no update as to how my liver may have fared since that time. This form noted that I had no liver failure or progressed chronic liver disease; no hepatocellular carcinoma; and did not require any ongoing screening for hepatocellular carcinoma or a liver transplant. I had had to wait until receipt of these forms for such reassurance as they contained.

EXHIBIT WITN0327007

79. In September 2004 whilst seeking the assistance of Dr Wilde in order to secure my medical records from the Queen Elizabeth Hospital, I received a list of the blood product batch numbers I had been treated from during the period 1978 to 1996.

EXHIBIT WITN0327008

80. The record, as mentioned above, actually only ran from 1981 until 1996 and was again, incomplete.

81. I fail to see how, or understand why my medical file has been 'lost' by the Queen Elizabeth Hospital. I find it alarming that such important information can be misplaced like this, rather than it having been disposed of in accordance with any form of hospital policy or procedural requirement placed upon the hospital by the NHS.

82. I am not only concerned that my file went missing, but that it did so at a time when the infection of people with haemophilia was becoming well known and when litigation was being considered and widely reported. I am also concerned that the records which remain accessible, are either incomplete, inaccurate, or both.

83. Finally, I would like to add that all of the issues I have faced came about at a time when my wife andI were trying to raise a family and at a time when I could least afford to have to deal with things I found it merely adding additional pressure to my, and our, daily lives.

Statement of Truth

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

Signed: GRO-B

Dated: 3rd January 2022