

Witness Name **GRO-B**

Statement No: WITN0173001

Exhibits: WITN0173002

Dated: 25 June 2019

INFECTED BLOOD INQUIRY

STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:

1. I am a person with Severe Haemophilia A (ranging between 1-2%) and I had become infected with Hepatitis B, HIV and Hepatitis C as a result of the receipt of contaminated Factor VIII concentrates.

Haemophilia A

2. I am termed as a spontaneous mutant of anti-Haemophilia Coagulation Deficiency in other words, there is no family history of Haemophilia A in my family.
3. I was born on the **GRO-B** 1971 and therefore am aged 47 years. There was a concern about bleeding **GRO-B** at 8 days old. A week later, I was admitted to hospital that resulted in my Factor VIII deficiency diagnosis. I understand that I had venous blood taken from my head for checking and clotting factors and thereafter there was a small swelling of the anterior fontanelle. At that time, I was given one unit of cryoprecipitate. The next morning, I now know from my medical notes that the lump was no larger and my parents were allowed to take me home.
4. I was thereafter formally diagnosed with Haemophilia A. At that time, I was under the care of **GRO-B** a Consultant Paediatrician at the **GRO-B**

GRO-B Hospital in GRO-B Most of my bleeds during my childhood were into target joints such as my ankles or knees. Generally, I was treated with cryoprecipitate and achieved haemostasis on that treatment. I had no allergic reactions to that treatment. I was an active child and, as time progressed, transferred to Factor VIII concentrates.

5. I was not initially permitted to embark upon my parents preferred first choice of Primary School (GRO-B Liverpool) due to my Haemophilia condition and therefore went to another school for my reception year. However, in my second year, GRO-B relented and I stayed at that school, both primary and secondary, for the remainder of my education until aged 18 years.
6. I believe that I commenced home treatment in or around 1978. I now know from the Medical Records, and indeed I recall, that I developed Hepatitis during my childhood. In May 1978, I developed serum Hepatitis which was known and appreciated by the Medical Practitioners as being attributable to the regular Factor VIII concentrates which I received. I note that in a letter dated 25th May 1979 there is reference to myself where it indicates that **GRO-B is a Haemophiliac and in May 1978 he developed serum Hepatitis which must be related to the regular Factor VIII he is receiving at home. He is Hepatitis BSAG positive.**
7. On 16th May 1978, Mr. GRO-B Consultant Paediatrician, wrote to my GP GRO-B and he indicated that ***"I suspect you will have heard that this boy has recently developed serum Hepatitis, which must be related to the regular Factor VIII he is receiving at home. We have seen him on several occasions with this and he remains unwell, nothing like his normal self. He is nauseated, with some vomiting, poor appetite and rather lethargic. His liver is considerably enlarged and of course he is markedly jaundiced. When I saw him on Friday, together with GRO-B he had some pain and discomfort in the left ankle, which was thickened. He had some haematuria. We had given him further bottles of Factor VIII. We have***

discussed the implications of [GRO-B] diagnosis with [GRO-B] and asked her to take extra precautions when injecting [GRO-B]."

I now realise, that in essence my mother was being informed that I was a Hepatitis transmission risk to her from that particular letter addressed to [GRO-B]. [GRO-B] Also, I now realise from the content of my Medical Record detail that I had become an unwell child.

8. It is with some interest that I note a letter in my Medical Records dated the 29th October 1976 where it was indicated that *"because of recent queries from the Central and Southern District administration concerning the expense of buying commercial clotting Factor concentrates, I feel that wherever possible we must initiate Home Therapy Programmes on the basis of cryoprecipitate. Mrs. [GRO-B] has a deep freeze, but is not sure of its temperature range. However, if this turns out to be satisfactory (and of course the BTS will have to be satisfied with this) I think we should encourage her to continue on the basis of cryoprecipitate at home, although we can get further concentrates for travel."*

In other words, the feasibility of cryoprecipitate as an alternative treatment option was known and appreciated at the relevant time in advance of my exposure to Hepatitis B.

9. More startlingly, I have noted in my Medical Records an entry that is undated but has a distinct entry 28/4 where the wording and handwritten notes headed "Dr. [GRO-B]" is in the following terms: -

"[GRO-B] Haem A 28/4 Report SRM – Hep B Positive. At this stage (unless test has been previously done) cannot tell whether recurrent jaundice is acute Hep B or ordinary Hep A superimposed on chronic Hep B positivity."

PH.LS would like to know the sources of F8 to let the makers know! Circularized by E.G.H."

That entry would appear to be a pre-cursor to a letter from Dr. **GRO-B** Consultant Paediatrician to Dr. **GRO-B** Public Health Laboratory Service, Liverpool.

The entire content of the letter is as follows: -

*"Dear Dr. **GRO-B***

We have heard from you this morning that this child is Hepatitis B. Positive. He is a Haemophiliac on regular home treatment. I enclose the Batch Numbers and source of his Factor VIII since November 1977.....

Yours sincerely,

GRO-B

Consultant Paediatrician

Date:

Batch No: "

10. It is very clear that in accordance with the terms of the handwritten notes in my Medical Records, the Public Health Laboratory Service were informed of my Hepatitis B status. Also, it is very clear that the purpose of informing them of that particular status was to allow in the terms of the note "to let the makers know!".
11. I now know on the basis of the Batch Nos. which I received during the time period concerned that those Batch Nos. related to a Factor VIII concentrate named Koate. I now understand and have been informed Factor VIII concentrate product named Koate was manufactured by a Pharmaceutical Company named Cutter. Also, I appreciate that that particular fractionator or manufacture of Factor VIII concentrates with a U.S. Pharmaceutical Company who manufactured Factor VIII concentrate from U.S. plasma derived products.
12. I wish to know as to whether the U.K. Public Health Laboratory Service informed Cutter that their Factor VIII concentrates in 1978 were transmitting Hepatitis B

infection or more particularly transmitted Hepatitis B infection to myself? If they did so inform Cutter, what was the response of Cutter and more particularly, did the Public Health Laboratory Service seek to have the Factor VIII concentrate manufactured by this Company withdrawn from the U.K. market? If not, why did that scenario not occur?

13. It should be noted that I, as a 7-year-old boy, developed serum Hepatitis which is noted in the correspondence set out above as having made me **unwell**. The extent of my illness was quite significant in that I was "**nauseated, with some vomiting, poor appetite and rather lethargic.**" Also, it is noted that my liver was "**considerably enlarged**" and that I was "**markedly jaundiced.**"

14. Also, it is noted that I was considered (subject to the suitability of my mother's freezer) to be a person who could receive cryoprecipitate home treatment to alleviate the consequences of my Haemophilia condition where that treatment option was more cost effective yet admittedly more cumbersome in terms of treatment.

15. I refer to Exhibit WITN0173002 which is a handwritten letter dated 28th April 1978 from **GRO-B** letter dated 16th May 1978 from **GRO-B** **GRO-B** and also, letter dated 29th October 1976 from **GRO-B** **GRO-B** **GRO-B**

16. It should be remembered that home treatment allowed people with Haemophilia to lead a relatively normal life. When I commenced home treatment, my mother was taught as to how to inject me. It was deemed at that time to be an essential tool in leading what in essence was hoped to be a normal life and also to avoid spending considerable periods of time in Hospital either receiving or awaiting treatment, particularly with cryoprecipitate.

17. GRO-B
- GRO-B
18. GRO-B

Hepatitis B

19. I was hospitalised for a significant period of time, with my Hepatitis B condition. I still remember that I was very jaundiced and that my skin turned yellow and I that I was isolated from other patients and placed in an isolation ward. I very much recall the Medical Practitioners talking about me and trying to explain how the events that resulted in my infection occurred. Also, I know now that they had linked that infection to my treatment with Factor VIII concentrate manufactured by Cutter Pharmaceutical Company. I don't believe that my parents received that level of information to allow them to be informed persons to make any further decisions necessary associated with my ongoing care. Also, I do recall Dr. Boulton instructing staff or personnel at Alder Hey in the treatment of my condition. I know that at that time there was a concern associated with a viral transmission risk from me.

HIV

20. I now wonder as to whether I became infected with HIV at the same time that I became infected with Hepatitis B. I am interested to ascertain as to whether any stored serum samples were taken from me at that time that would allow a retrospective analysis to occur as to what was my date of initial HIV infection. I know that my mother GRO-B was first informed of my HIV diagnosis by Dr. GRO-B who had then replaced Dr. GRO-B at the Royal Liverpool Hospital before GRO-B sent out formal letters to my parents. I understand from speaking to my father that they were then called to a group meeting (with all other parents in a similar situation) where a scientist was in attendance to deliver information. At that meeting they were informed of the

percentage chance that the infection would be fatal i.e. in other words that their child had contracted HIV and the consequences that might occur in terms of reduced life expectancy or death.

21. I know from my Medical Record detail that blood was taken for HTLV3 screening (the forerunner to HIV) on 5th August 1985. Also, I know from my Medical Record detail that I was noted as at 28th August 1986 as being HTLV3 i.e. HIV positive.

22. Also, I note in my Medical Records a letter from Dr. GRO-B Consultant Paediatrician, addressed to whom it may concern in the following terms: -

"this young man who has Haemophilia is also HTLV3 positive. Care should be taken in doing any procedure that would involve exposure to his blood. Further advice can be obtained from GRO-B Hospital, Extension 294 or 419."

During that time period I suffered with a significant number of nose bleeds. Those nose bleeds required a lot of packing of my nose and numerous doses of Factor VIII concentrates. In essence, I was a HIV transmission risk to my family.

23. Undoubtedly, it was a terrible shock for my parents and indeed, a very difficult issue for them to address with myself. It should be appreciated that this devastating news was at the height of the AIDS campaigns promoted by the Department of Health in the media to minimise risk of transmission of HIV where black tombstones were the order of the day. Most of the information that I gleaned at that time I ascertained from the media comment which was equally sensational. I associated HIV with AIDS, AIDS with death and I knew that I had received a death sentence and that life itself was like a ticking time bomb ticking away. I can vividly recall as if yesterday watching the T.V. news after the then prominent film star Rock Hudson had died from the consequences of AIDS. It was a frightening time where hysteria was created, and I was the recipient of the then attitude that existed as a young teenager, who had neither the maturity

nor life experience to understand or address the issues that were existing for myself.

24. Accordingly, I squirrelled myself away. Although my parents are kind, sensitive persons, they were somewhat old-fashioned and very much immersed in the traditions of [GRO-B] Due to the stigma, potential ostracisation and indeed, the consequences for my family both within the wider community and [GRO-B] I kept the deadly secret of my HIV diagnosis. With the exception of my sister and uncle, as a family we did not share my HIV diagnosis within the wider family. It was a taboo subject and it was an issue that was difficult to discuss. [GRO-B]
[GRO-B] Even my kind, sensitive and understanding family were treating me differently due to the hysteria that existed. I felt like a leper.

25. Any time I became in any way ill, it was very concerning for both myself and my family. I knew and realised that the fears that existed at that time were that the beginning of an illness could be the beginning of the end of life itself. I am now a father myself and accordingly I have a greater understanding of how that terrible burden must have affected my parents. I know that my father's [GRO-B] practice suffered significant damage as a result.

26. I never told any of my school colleagues of my HIV diagnosis, not even my closest friends; in essence I lived a lie to maintain a secret. I approached my pending 'O' Levels with the thoughts of *'what is the point of this exam if I am going to die anyway.'* However, against hope, I thought maybe I should prove something to myself and so focused on my academic studies. At that time, I was continuously being asked by school friends, who knew of my heamophilic condition, whether I had AIDS and also whether I was going to die?

27. I took the attitude that life would be short, and I tried to take as pragmatic a view as could be achieved in the context of a death sentence. I wanted to take what I could from life itself as I thought I was going to die and that it was likely on the

basis of the hysteria that then existed that that death would be sooner rather than later. Somewhat surprisingly, I managed to achieve reasonable exam results and I can recall my mother bursting into tears and indicating that she thought that she would never see that day.

28. I therefore approached life with much more positivity although my apprehension over my condition was never far from my mind or indeed my thoughts. As I then approached my A Levels, I was deeply affected by the Hillsborough disaster in April 1989. GRO-B

GRO-B Yet again, I felt somewhat guilty in surviving when I was already under my own death sentence and indeed in some way a better sacrifice than others. Accordingly, it made no sense to me that innocent young people died yet I, with my death sentence, survived that awful, horrific day.

29. My uncle (with whom I was as close to as my father) was a successful GRO-B GRO-B and that particular image and profession always excited me as a future career prospect. I therefore decided I wanted to attend University to study GRO-B I went to the University of Leeds from 1989-1992 graduating with an GRO-B

30. During this time period, I suffered from oral thrush. At this time, my CD4 counts were low as I was offered the prospect of what then was the treatment of choice being AZT or Zidovudine, which was both a trial and maybe even an unlicensed drug.

31. At University, I hit a crisis. I found it a very isolating experience as I was living a lie and holding a terrible secret. GRO-B

GRO-B
I was feeling very low in or about 1990-1991 and eventually two of my very close friends realised there was a significant problem and accordingly I confided in them. They were the very first people I had ever disclosed my condition to. Immediately I regretted telling them as it was a very emotional

time and I appreciated or realised that I had placed an impossible burden upon them by telling them this secret. Also, there was a significant amount of ignorance, prejudice and hysteria around that time fuelled by media hysteria and I never had the confidence that the disclosure of my secret would be maintained but the persons concerned were very kind and honoured the trust that I reposed in them where they have retained that secret to this day and remain friends.

32. Obviously, University is not only for educational achievement but is also an opportunity for personal development and social interaction. I felt that, due to my HIV diagnosis, I could not fully indulge in all the opportunities that University afforded to students. At that time, I never countenanced nor was I interested in forming any relationships as I knew that I was a HIV transmission risk.

33

GRO-B

34. To this day, I am extremely fearful that any person may find out about my HIV condition or indeed my general infected status. As I indicated, I shied away from relationships at the time and was not confident

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my

sister (who is 6 years older than me)

GRO-B

 was involved in two long term relationships and when she confided to them my HIV diagnosis status, both parties to those relationships called off their courtship with her. Consequently, my HIV diagnosis or infected status has not only affected and had impact for my parents, it has affected my entire family in different ways with very serious consequences.

35. As indicated, I took AZT and suffered many of the awful side effects of that trial medication such as gastric problems, nausea etc. During what ought to have

been my carefree years i.e. my early 20s I had to take so many tablets with significant adverse side effects that that medication itself altered my quality of life. Also, I found it difficult to explain my various absences from work due to illnesses or side effects of treatment and I became or at least was perceived to be someone less than reliable.

36. In 1995, a friend was working in the United States and both myself and another friend arranged to visit him. I realised that due to my HIV status, I was required by virtue of U.S. Federal Law to complete a Waiver Form, but I was assured that it would be alright to travel even though I had not received confirmation of the waiver. I arrived at Newark, New York with my travelling companion (who I had not told of my HIV diagnosis). My friend went straight through Customs but I was pulled to one side and because the Waiver had not yet been processed, I was refused entry into the United States and sent back to the UK on the next plane. I spent time in a holding cell during the period it took to arrange my repatriation to the United Kingdom.

37. On my return, it was deeply embarrassing having to attempt to explain away what had happened where I had to be less than candid to friends and colleagues as to why I had returned home whilst my companion remained in the United States. Such a scenario was extremely difficult given that the cohort of people GRO-B GRO-B were aware of how life worked. That scenario meant that I now lived life on the edge for fear of discovery.

38. Considering my recent discoveries from my Medical Record detail, it is somewhat ironic that I should be treated in the manner in which I found myself in the United States by U.S. Federal Authorities yet the exact same Federal Authorities allowed a scenario to occur where plasma was collected from high risk sources including prisons and from high risk persons by U.S. Fractionators or Pharmaceutical Companies that resulted in the export of those Factor concentrates to the United Kingdom that caused my infections. I now know that

my Hepatitis B infection was caused in all likelihood by receipt of a Factor VIII concentrate manufactured by the U.S. Pharmaceutical Company, Cutter.

39. I am aware of comment that Bayer Corporation and its' Cutter Biological Division realised that their blood products, Factor VIII concentrates, were contaminated with Human Immunodeficiency Virus (HIV), and that they exported those products outside the United States. Also, I am aware that from March 1983, Cutter had a heat-treated Factor VIII concentrate that eliminated the risk of transmission of HIV infection or AIDS. I understand even after the introduction of safe heat-treated Factor VIII concentrates, Cutter exported its non-heat-treated Factor VIII concentrates.

40. I now know that on 16th July 1982, the United States Centre for Disease Control & Prevention (CDC) reported that three people with Haemophilia had acquired the AIDS disease. Accordingly, Epidemiologists believed that AIDS was being spread through blood products, with grave implications for people with Haemophilia such as myself who had routinely or were routinely injecting themselves with Factor concentrates made from large pools of donated plasma, much of which was collected at commercial plasma locations from high risk sources and prior to routine HIV testing occurring. Some of those collection facilities were located in cities that had large numbers of homosexuals, intravenous drug users and indeed, in some U.S. prisons such as Arkansas.

41. A very significant chronology of events exists in terms of the evolution of knowledge associated with the risk of transmission of AIDS. By March 1983, the CDC warned that blood products "*appear responsible for AIDS amongst Haemophilia patients.*" By May 1983, France had decided to halt all clotting Factor concentrate imports.

42. Accordingly, considering the knowledge and appreciation of the various Pharmaceutical Companies, I must question as to whether those Companies ought to have withdrawn or indeed recalled Factor VIII concentrates from the U.K. Market. Also, as to whether only heat-treated Factor VIII concentrates

ought to have been utilised at a much earlier date than was the situation in the United Kingdom.

43. The circumstances surrounding my treatment at the hands of the U.S. Federal Authorities is in contradiction to their proactivity in addressing the contamination of Factor VIII concentrates which I received. Also, the Company that was responsible for my HIV infection is part of a larger Pharmaceutical conglomerate which ought to be held, I believe, to account or at least to explain the issues that have occurred resulting in my various viral infections

44. Due to my triple therapy treatment, I suffered various and appalling side effects of that treatment including in the early days gastric problems, nausea, weight and fat redistribution etc. As a consequence of these side effects including diarrhoea, I could not always **GRO-B** and therefore I appeared somewhat unreliable. On occasions I had experience of **GRO-B** **GRO-B** not making it to the toilet in time. Such an experience was deeply humiliating and indeed somewhat shameful for myself. Also, I suffered other more marked side effects such as lipodystrophic redistribution of fats. Accordingly, I have a large neck, hump on my shoulders, inverted cheeks where my facial contours have significantly changed and indeed altered due to the redistribution of fat that has occurred. Accordingly, I opted for plastic surgery in an attempt to minimise and reduce the effects of such redistribution to endeavour to achieve a more normal facial appearance. In addition, certain other side effects are quite apparent from these treatments including disturbed sleep pattern, nausea etc.

45. The most marked effect is the fat redistribution which has changed my facial appearance and has resulted in certain comments; **GRO-B**
GRO-B

46. Accordingly, I underwent surgery. In essence, fat was sucked out and redistributed to try and create a more normal appearance. Although, I had received this treatment on the NHS, it wasn't effective. After two or three

attempts at fat redistribution or plastic surgery intervention, I underwent private plastic surgical intervention, but it had no better or improved effect.

47. Also, a consequence of the treatments that I had been prescribed for my HIV condition, which are life-saving admittedly, are cholesterol related problems. I have been admitted to hospital, as an emergency, on a number of occasions due to tachycardia issues. Accordingly, I have concerns in relation to vascular issues, I am aware that I am at risk of further cardiac and vascular problems. This is somewhat ironic in that those particular risk factors are extremely low in the context of Haemophilia. In those circumstances, my treatment itself has a life-limiting effect without reference to my conditions limiting life expectancy.

48. Also, I look very different now cosmetically to that of some 10 years ago due to the fat redistribution on my face, neck, back, etc. as a result of my HIV protease inhibitor treatment. The comments that have been made have been somewhat hurtful, the effects in terms of my confidence have been somewhat negative and my ability to maintain my career has been affected by both my lack of reliability due to my health-related issues and most particularly by both my appearance and perceived unreliability.

Hepatitis C

49. Once I turned 18, my treatment had been transferred to the Royal Liverpool Hospital. Every time I attended for an appointment, all I could think about were the HIV viral load numbers. Although, the Hospital soon employed Specialist Nurses, I was never comfortable in speaking to them about personal relationship type issues, most particularly relating to HIV viral transmission risk.

50. I was not diagnosed with Hepatitis C until the 1990s. I now had the feeling that I had two serious infections and if one did not get me, then the other would. Also, I had regular attendances at Hospital where the HIV had previously been dominating my mind and now I required to concern myself over another equally serious and potentially terminal illness.

51. I have suffered very significant liver damage as a result of the Hepatitis viral infections although I had treatments including interferon that did not work where the side effects were terrible, and I suffered from depression as a result of that treatment. Eventually, and after many trials and tribulations, one of the cycle of treatments was successful.

52. I did receive letters concerning potential infection with vCJD from the Department of Health and this was and continues to be disturbing. Again, the press hysteria has been difficult to deal with and most particularly the psychological effect of the label "Mad Cow Disease" or scaremongering. Another layer of potential exposure and another thing to worry about. Now I have a family this is even more worrying.

The Present & Future

53. I was very fortunate to survive as many others have not, but my HIV infected status has had a devastating impact on my life.

54. The Hepatitis C infection has also had a severe impact on me. I was tired and unwell and had depression.

55. In 1997, I met GRO-B my first and only partner. She has been on this journey with me and I could not have imagined happiness without her. The decision we made together to have children was perhaps the most long and difficult journey. I was very fortunate to have met my partner, but I was extremely worried that I would pass my infected status to her. I was never willing to risk her health by trying for a baby naturally.

56. Our children (now GRO-B) are a blessing and the joy of our life. We are so very lucky to have been able to afford to fund the various treatments required to have them. However, it has not come without a personal cost and not just

the significant amount of money we spent but the cost to **GRO-B** emotionally. My daughter was born after 7 IVF attempts. Each failed attempt was a devastating blow. After a further two attempts, our son was born. Also, sperm washing was an inevitable and safe requirement.

57. The treatments to enable us to have children was continually swathed in secrecy as people asked why we were needing IVF and travelling to see Consultants outside the Merseyside area. I was fearful that my HIV infected status would come out. This had its own burden during a stressful period.

58. We had to travel to London as the "sperm washing treatment" was under the care of the Chelsea and Westminster Hospital. This necessitated overnight stays that added to the cost burden and also professionally meant I had to turn **GRO-B** down work. The trips and treatment were long and traumatic and, save for the first IVF treatment, the rest were funded privately. We applied for extra funding but were refused. This felt like a double blow as my infected status was inflicted upon me as a child. It felt like punishment. We were fortunate that I was able to work and plough the money we had into achieving our dream of having children and this has never given me a moments regret.

Macfarlane & Skipton Trust

59. I did receive payment from the MacFarlane Trust and the Skipton Fund.

60. However, the MacFarlane Trust was means tested and so due to my earnings, I never have qualified for any additional payments.

61. **GRO-B** has caused considerable problems within my family. For a period of time, my relationship with my parents suffered and my sister would not speak to me. Given all the issues we had gone through with my HIV/Hepatitis C diagnosis, this was particularly upsetting as I genuinely believed that they would be happy for me that I had now met someone who loved their son/brother. Over time, things gradually improved. My mother

ANONYMOUS

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HIV/Hepatitis C diagnosis, this was particularly upsetting as I genuinely believed that they would be happy for me that I had now met someone who loved their son/brother. Over time, things gradually improved. My mother became ill with cancer and this changed the family's perspective. Sadly, she has now passed away.

64. There have been very difficult times as the funding of our children's conception caused financial difficulties as did the travel and hotel bills. As I was self-employed, I could take time to do this but I know that this period, together with the illnesses and time taken off for my hospital treatments has significantly impacted on my career and my level of earnings could have been far greater.

65. When I look at what I have managed to achieve, despite the obstacles, I know I could have achieved much more professionally.

66. Keeping the secret, both personally but also professionally, has weighed very heavily on my mind and I was extremely frightened that there would be ignorance and prejudice if my infected status was discovered and that instructions would dry up, leaving me and my family without income.

67.

GRO-B

Statement of Truth:

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

Dated the 25th day of June 2019

Signed:

GRO-B