ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1011001

Exhibits: N/A

Dated: 1 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B of GRO-B, Essex, GRO-B make this Statement for the benefit of the Infected Blood Inquiry in relation to the circumstances surrounding both my exposure to Hepatitis C infection and the consequences so arising.

1. I am a person with a bleeding disorder, which is a bleeding disorder that is somewhat unique in that it is a Factor XI deficiency at around 3% in circumstances where, the treatments that I have been prescribed in relation to both blood and blood products have been varied.

2. The beginning of my difficulties was in or around 1979 when I was diagnosed with ulcerative colitis after a period of four weeks of illness. That diagnosis resulted in my admission to the Royal London Homeopathic Hospital (RLHH) for approximately 8 weeks, and a further 6 weeks after that. During that admission, I received both blood transfusions and fresh frozen plasma. Obviously, both of those products are blood products that have a limited exposure to donors in comparison to either Factor VIII or Factor IX concentrates which are multi-donor pooled concentrates.

3. Interestingly, whilst at the RLHH, I recall a Consultant indicating that I was not to receive any transfusions where also he was of the view that an administration of a blood transfusion had been inappropriate. I don't

understand why he had such a perception, but I have often wondered as to why such a view existed, most especially in the context of the events that subsequently happened.

4. In September 1980, I underwent surgical intervention at University College Hospital London where at that stage I was aged 19 years, the procedure was a Pan Procto Colectomy with formation of ileostomy. Although I would have underwent informed consent for the procedure, I did not receive any information associated with risk of transmission of any viral agent or non-viral agent from blood or blood products prior to this procedure.

5. Also, after the surgical intervention, I suffered a massive haemorrhage which required 12 units of blood and more crucially, the administration of Factor VIII clotting agent. To this day, I don't know whether I received a Factor VIII concentrate or cryoprecipitate. I recall significant volumes of both blood and blood products being administered from a bag into my arm. I was extremely unwell and my ability to understand or recall the detail due to my ill health was compromised.

6. During that hospitalisation period, I was diagnosed with a Factor deficiency but an unusual Factor deficiency in that it was Factor XI with a level of around 3%. I understand that that particular level of deficiency is very severe and therefore one of the essential constituent clotting Factors necessary to achieve haemostasis or clotting is almost not present.

7. At some point, the multi-disciplinary Team started to include the contribution or involvement of a Consultant Haematologist. I was informed that it was necessary for me to receive large volumes of Factor VIII agent to ensure that haemostasis could be achieved. The pressure to get the blood product into my system was such that the bags within which the product came were squeezed to force the volume into my body. I was also aware that it was quite a painful process and the explanation that was

delivered was that volume needed to be achieved to manage a clotting situation.

8. Fortuitously, the experimentation which is the term that was used to me in terms of achieving haemostasis was successful. After discharge from University College Hospital London, I was required to reattend the Haematology Unit. Further tests were undertaken to ascertain which product was most suitable in terms of achieving Factor XI levels for clotting. Also, I was called subsequently for surgery for pelvic abscesses and in that instance, I was given fresh frozen plasma before surgery but on two occasions the Factor XI levels were too low to allow haemostasis to be achieved and therefore I was at risk of a bleed out during the course of the procedure and the procedure itself had to be cancelled. Unfortunately, these pelvic abscesses could never be properly addressed by surgical intervention and therefore, I was warned that that consequence could result in difficulties with conception. I tried alternative remedies, as one does when in desperation, to achieve the best outcome possible.

9. Also, because of the volume of fresh frozen plasma, and indeed its own impurities, I developed a severe allergic reaction to it which as I recall on one occasion that my eyes swelled up, I developed an itch across my body and on another occasion due to the allergic reaction it progressed to anaphylactic shock. In short, the treatment was not exactly the most pure or effective. Indeed, the old requirements of safety, efficacy and purity did not exist in the context of this treatment.

10. In retrospect, I believe that I was too complex of a haematological patient for University College Hospital London and therefore was transferred to the Haemophilia Centre at the Royal Free Hospital, London. I came under the care of initially Dr. Peter Kernoff, Professor of Haematology at that Centre. It was a Centre that had a specialist knowledge of inherited coagulation disorders that would have included Factor XI which was more prevalent in the Jewish community.

Personal Life

11. Obviously, like all young people, I was enjoying life and met a boyfriend at aged 15 who I subsequently married, and we wished to have children together. Also, I pursued a career subsequent to the Hospital interventions mentioned above and qualified as a Healthcare Professional in 1986. At around that time, both of us were very cognisant that a new addition to our family was a very desirable outcome yet after six months we knew that this was not working out in the manner in which we desired. Immediately after six months due to the pelvic abscess difficulties, we were advised that we should then be referred to a Fertility Clinic. That referral yet again was to the Royal Free Hospital where that referral occurred in 1987. From that period onwards, I was referred for IVF which would have been very much in its innovative stage. The rationale for that treatment was that both my Fallopian tubes had been damaged. Part of the IVF treatment consequence was the necessity for Factor XI treatment to achieve haemostasis. In other words, my IVF treatment resulted in the necessity for blood product treatment with its consequent risks. That treatment at that time was a Factor XI concentrate with all the attended risks that existed.

12. Obviously, for a young couple, that was a very grave, traumatic and stressful period.

13. As I was a private patient, we decided that we wished to engage the foremost Professor of Embryology at that time who was Professor Winston and he was located at the Royal Hammersmith Hospital, London. IVF was not available on the NHS at the time. I underwent more than 8 attempts including hyperstimulation and frozen embryos, all of which required the necessity of clotting treatments for each cycle.

14. Obviously during the late 1980s, the risk of HIV infection and blood borne viruses or blood borne pathogens was becoming much more apparent. Although I worked in the healthcare sector, my knowledge base was not associated with transmission risks and I was no different to any other patient. It came as a surprise after around 7 cycles of IVF treatment, that a young Doctor casually indicated to me that "*you have received an awful lot of blood products, I think it would be a good idea for you to be tested as there are many viruses out there.*" Accordingly, she advised me to attend at the Royal Free Hospital on the next occasion and seek appropriate testing.

15. In 1995 during a routine consultation with my Consultant Haematologist who was then Dr. Christine Lee, Professor of Haematology at that Hospital, she mentioned that I had contracted Hepatitis C, it was potentially life threatening and that I had carried the virus for anything up to 15 years at that stage. Professor Lee delivered the diagnosis in a manner where it was very matter of fact. Inevitably, I was somewhat shocked by that particular diagnosis. I proceeded to explain to her that I felt well and in essence, questioned her diagnosis which resulted in a very blunt response that just because I felt well did not indicate good health as many persons live with it and without knowing it and that I could have very severe liver damage. In essence, it was like taking a sledgehammer to crack a nut in terms of the manner in which the diagnosis explanation was delivered. Also, I was delivered a leaflet that explained the risks of liver damage, liver cirrhosis, the compensated cirrhosis and liver cancer. It didn't exactly alleviate my concerns but added to my trauma. Also, I realised that there was a risk of transmission to my husband and in addition, I realised that future conceptions, if they could occur, might result in transmission to any child or children. In short, I left that meeting in absolute emotional turmoil with my world turned upside down and inside out. My attitude towards conception completely changed in that I moved from wanting to conceive to arriving at a situation where I was relieved that I hadn't conceived as I could have infected an unborn child. I was left in an absolute whirlwind of emotion.

16. Then the waiting commenced because I didn't know how serious was my situation. Obviously, one believes the worst, as is the normal perception in life when one receives a terminal illness diagnosis. I remember thinking that I might have contracted more than a virus in that it could have progressed to liver cirrhosis, liver cancer or that I could have infected my husband. Up until that point in time, I had felt so fortunate to have survived a major illness and indeed the surgery associated with it and now it was apparent that I hadn't really survived it but all I had done was acquired additional time. Also, I had believed that I had been fortunate not to have contracted HIV having had two previous HIV negative test results when the transmission risk associated with HIV and blood products was in the news. I received no support from the Royal Free Hospital, I dealt with the consequences in my head as best I could as I didn't wish to create any anxieties, but I was undoubtedly agitated, broke down in tears a lot and moved towards anger as it dawned on me how I and my potential family or my husband had been placed at risk for all of these years. Also, when I realised that nobody had moved in any way to protect or minimise the risk of transmission, my anger was further heightened. That is even avoiding the situation that I received a blood product at a time when it ought to have been known that there was a risk of transmission attached to it. I could never rationalise in any logical manner how a healthcare body or indeed individuals could be so irresponsible to place both me, my husband and any potential children at risk.

17. That period lasted a number of weeks or seemed in my mind to last an interminable period but fortuitously the test results came back indicating that my liver was working well, and the blunt terminology utilised by Professor Lee did not come to pass but I still had major concerns and I had a basis for those concerns arising from my diagnosis. Although my liver was deemed to be working well I believe that at that time there were some signs that my liver was not 100%, which is why I am of the view that is the reason why I was nominated for the trial.

18. Yet, in or around six months after that diagnosis of Hepatitis C resulted in the Team at the Royal Hammersmith Hospital deciding that it was now time to end my journey with IVF. It was suggested that I look at alternatives. I didn't realise that there was an unwritten, or maybe written, rule that a Fertility Clinic should not facilitate conception in relation to a parent who had a potentially terminal illness as that parent may not be around to mind the child so conceived. It may be an ethical rule, but it may explain the encouragement that I received to look at alternative options. Anyway, IVF had been complicated by my altered anatomy, so I don't know to this day as to whether that decision that was linked to my Hepatitis C status would or did prevent conception. Yet, it was a clinical decision that prevented the prospect of conceiving a child that we so much wished to occur. All of the options that were being considered by the Royal Hammersmith Hospital stopped soon after my Hepatitis C diagnosis and therefore the prospects that I had so wished to occur were removed and lost to us.

19. Unknown to the Royal Hammersmith Hospital and indeed the Social Services we had also as a couple been pursuing the option of adopting children. The perspective of Social Services is to the effect that if one is pursuing IVF, one does not have the necessary commitment to adoption and therefore one should not be entitled to so do. Yet the reality is that if one does not adopt before a certain age, one loses the prospect of achieving an adoption. Consequently, we were forced into maintaining both options in the event of the issues that existed associated with IVF, although same was done in secret.

20. The IVF conclusion resulted in our doubling in our efforts at adoption as both of us were determined to have children and we were lucky in that we had completed our home study and were waiting for a child placement.

21. The timing of events yet again took a twist that was both unfortunate, traumatic and difficult in that in 1997, I commenced one of the most invasive treatments possible in terms of a clinical trial of both Pegylated

Interferon and Ribavirin at the Royal Free Hospital. At that time, it was a new, untested treatment, I believe unlicensed and no-one knew as to whether it could be effective. Also, I was required to inject myself twice per week with a drug regimen that caused serious consequences where I knew each time I took the injection that I was effectively making myself unwell. The treatment was horrendous, its side effects debilitating and included loss of weight, I lost in the region of two stone and I didn't have two stone to lose, I suffered hair loss which is difficult for any woman, skin cracks in both hands and most notably around my mouth, mouth ulcers that caused discomfort around food consumption, deterioration in my eyesight, excessive fatigue, night sweats, aches and pains and all the type of consequences that one would not wish on any person. At night my sleep was disturbed in that I couldn't achieve a good night's sleep due to the severity of itching and flu like symptoms associated with the injections. My attitude to life changed in that I became somewhat intolerant and indeed depressed at times and suffered all the consequences of mood swings that result in difficulties in relation to any environment, most especially a home environment.

22. My life was on a trajectory, but it wasn't an upward trajectory, but a downward trajectory associated with the side effects of the treatment concerned. That treatment had a further effect in that it impacted upon my business activities which were quite successful up until that time in that I was in private practice with a partner where up until that period I had pulled more than my own weight. The effect of the treatment was that it was obvious that I could no longer work full-time. I tried to mitigate the situation by taking over administrative aspects of the business rather than client related obligations. Initially my business partner was prepared to accept this division of responsibility as it was envisaged that I would return to my original activities in terms of being a full partner with a full responsibility for business development etc. Due to my fatigue, poor sleep pattern, lack of concentration and inability to contribute to any extent in the business, eventually my business partner took over the entire running of the business which was hoped to be a short-term solution. It

was envisaged that after a few months that I would return and take up where I had left off.

23. The Pegylated Interferon/Ribavirin treatment exacerbated the fatigue that I had previously experienced to the extent that I became completely ineffectual and unable to undertake the obligations associated with my business. I was in a business that was somewhat unique in that I was very much to the forefront in the development of Occupational Therapy private practice in a medico-legal environment and social care. During that time there were very few Occupational Therapist's working privately in social care. My work involved meeting disabled clients in their homes, doing assessments of their needs and writing Reports. I also managed a Team of OTs and proofread their Reports and supervised them. In essence, I was one of the two key lynchpins to the organisation or business concerned and it was growing where, we were somewhat innovative in that we were quantifying the level of care required from the family and commercial organisations and also quantifying their housing, adaptations, equipment and holiday needs. Also, we were obtaining Contracts from Local Authorities and the business was growing.

24. Fortuitously, Social Services offered us two children for adoption during the course of this Hepatitis C treatment. At that time, I had nine months to go but I had cleared the virus and the issue was my ability to maintain the treatment to achieve a sustained viral response so that I could be alive for these two adoptive children. As I had disclosed my Hepatitis C status to Social Services, they wished to be certain that the treatment both worked in terms of achieving a Hepatitis C viral negative status and furthermore a sustained viral response. In short, I had to prioritise my focus not only in terms of providing a home for the two children concerned during treatment but also ensuring that I would complete the treatment to achieve the sustained viral response.

25. Unfortunately, the cost of that endeavour was my inability to maintain my business. It got sacrificed in that I didn't have the capacity to do the work

and undoubtedly my partner for understandable reasons to some extent, decided that I was no longer of benefit to that business. Accordingly, within six months of the treatment I had no alternative but to sell my business to my business partner. The cost achieved was extremely low, but I knew that I could never even return on a part-time basis. Also, my priorities were my health and my ability to achieve a sustained viral response. The business split was acrimonious as my partner felt he had been carrying me for many, many months and felt that I had let him down by not returning to the workplace. The price achieved for the business reflected the acrimonious situation that existed, the captive nature of the business transaction and my own inability in terms of energy to seek any alternative options. It was my health or the consequences of my health treatment that prevented me being able to juggle both business commitments and my adoptive children.

26. Although I ceased treatment after one year, it took a considerable time, maybe 6-12 months for the effects of both Pegylated Interferon and Ribavirin to reduce in my body. The joy of having two little people in my life was tempered to some extent by the effects of poor health, my mood swings and excessive fatigue. Yet having two 2-year-old children is a demanding obligation in good health but impossible to achieve in bad health. I trundled through it with the assistance of my husband GRO-B who had to reduce his workload and curtail his career to achieve the necessary support for both of our two children. My health although it improved as time progressed, still was compromised in that I suffered with fatigue, aches and pains and I was on a very slow trajectory, this time upwards, towards recovery or as good as could be achieved. Yet I had to manage two young children where on occasions, in order to get them to sleep, I would get into the car and drive them long distances which wouldn't have been the best situation to undertake in the context of my tiredness, lack of concentration etc. but it was an indication of desperation of a different nature.

27. Also, due to the skin cracks, nappy changing was something that I couldn't undertake. Also, I couldn't bathe them without help. In addition, I found it difficult to cuddle or hold them due to the pain and I also had to wear latex gloves given to me by the Hospital to prevent contamination occurring when cracks were really bad. Yet, young babies don't like mothers handling them in gloves as it is not natural nor normal. My energy levels curtailed my ability to participate in usual activities with young children like playing. Also, my love of arts and crafts which I would have utilised to entertain them wasn't available. Also, I am proficient in piano and I wasn't able to play the piano to entertain them. As time progressed, I felt absolutely useless as I couldn't even do the basic activities such as changing nappies, bathing, entertaining two young and demanding people.

28. Also, unlike other mothers, I had to attend Hospital appointments, there was a necessity to bring my two 2-year-olds to those appointments. The journey would be 1½ hours each way where it was hard to keep children entertained in the back of the car for such a journey and thereafter to keep them in any way behaved in the context of a medical appointment that often didn't occur at the allotted time period. Both children often became fretful, excessively tired, tearful with the effect that that would have both on them and on myself. My mother had to attend these appointments with me as I found it difficult to cope by myself. Also, I would often meet with others at this drug trial who were not having any success which would bring into focus the prospect that my own treatment might fail and therefore I would lose not only the quest for life itself but the quest to keep these precious children with me. Also, I realised that the consequence of failure of treatment was potential liver failure, liver transplant and even death. Each week, I realised that people fell away from the trial as it wasn't working for them and now I know that many of them have since died. I was fortunate to beat the odds at a time when many people didn't achieve it.

29. Also, but for the support of my husband, who reduced his working hours and indeed, compromised his own career to the extent that he was made redundant, we wouldn't have been able to manage our two young children. We believe that my husband's career redundancy was directly related to his need to be available to help me during my treatment situation. Understandably in a very competitive banking environment, he was considered to be no longer effective as he was unreliable in terms of his duties due to his requirement to assist me and inability to undertake the necessary long hours prevalent in that sector.

30. As time progressed after treatment ceased, my health improved. My work obligations in the home still remained where I was utilising all energy available to me to be able to care for two very young children. Yet, financial reality necessitated that I would return to work on a part-time basis. It was necessary to be able to juggle my lack of energy, my childcare obligations and a work output that facilitated that scenario. Accordingly, I returned to part-time work as an Expert Witness which allowed me to undertake work when I had the energy to so do. As time progressed I increased my hours and yet again my work obligations started to increase and by the time both children started full-time education I was starting to resume some normality. Yet it should be emphasised, that I never got back to where I had previously been in terms of my business enterprise and the financial return that I achieved for my Expert Witness work was very insignificant in comparison to my previous employment. I had moved from being the employer to become the sub-contractor at a significantly lesser rate.

31. Officially, I retired as an Expert Witness at aged 57 years. That is early by anyone's standards and I directly attribute that retirement to my health issues associated with lack of energy, poor sleep which has continued since treatment, lack of concentration and difficulties fulfilling the obligations attached to work obligations. Also, my ability to address the stresses, pressures and tribulations of work was diminishing as time progressed.

32. I believe but for the consequences of Hepatitis C infection, I would have continued my business activities. I would have also had an asset to sell when the time was right or receive an income into older age. Also, my husband would not have been made redundant from his job in the banking sector and our financial situation as a family would be significantly better than it is today. Admittedly, we have managed to survive and indeed, we have achieved well in life considering the unfortunate events that occurred, but those events occurred through no fault of our own as our life path was irretrievably altered arising from the effects of Hepatitis C. Also, even after all my turmoil, I received the opportunity of a further business partnership, but I realised that I couldn't countenance it due to my lack of energy and inability to fulfil the necessary work obligations which would be unfair to the person with whom I would enter into partnership. I may have the innate ability and present well at times, but I know deep down that the engine doesn't run to the requisite extent necessary.

33. After 5 years I eventually reached the situation where I was informed by the Royal Free Hospital that there was no requirement for further Hepatitis C testing and I was now to be discharged. A couple of follow up tests for Hepatitis C only took place at my request. Up until that time period I found returning for such tests extremely stressful as I was also always fearful that a Hepatitis C positive test result would materialise. The lead up to the test and the aftermath in waiting for the result were difficult as I was required to focus upon mortality yet again.

34. Although I have been discharged, I now realise that maybe that might not have been the most appropriate course in that I understand there is a significant risk of liver cancer materialising and in more recent times I have arranged with my GP for ongoing monitoring of Liver Function Test results and most particularly Alpha Feto Protein test results to ensure that no liver cancer goes undiagnosed. Also, I have arranged for scans to be undertaken so that I can protect my own health. I am somewhat surprised that I was discharged from the Royal Free Hospital where I understand

that other Hospitals continued the protocol even after a Hepatitis C virus negative test result of continuously reviewing patients for risk of cancers which are more prevalent in the context of my situation. Yet, somewhat ironically, I still continue to attend the Haematology Centre at the Royal Free in relation to my Factor XI deficiency every two years and by phone during the alternate years. Surely it would be as easy to undertake the range of Liver Function Tests necessary and scans required during the course of that annual review to ensure my continued health and well-being.

35. Also, I should note that much of my Medical Record detail has been lost. That affected various aspects of my life and I must question as to why Medical Records are not preserved as a matter of obligation on the part of the Hospital considering the technological advances that now exist. Surely if a patient is still alive, attending a Hospital, it is necessary that the complete Medical Records of that patient should be available until that patient leaves the charge of the Hospital concerned. I would even contend, that for future generations, considering my bleeding disorder, that it is preferable that such Medical Record detail is scanned and preserved to ensure that it is available for extended family members if so required. I was informed on one instance that my Hospital Notes had been entered on a Hospital system but couldn't be retrieved. What that means is uncertain.

36. Accordingly, I have a number of issues that I would like the Infected Blood Inquiry to address which are as follows: -

1. Why did I receive a contaminated blood product without any advice as to the risk associated with that blood product concerned?
2. Were there any other synthetic alternatives available at the date of receipt of that contaminated blood product that would have avoided Hepatitis Non-A Non-B infection?

3. Why wasn't I made aware that as far back as 1978, that various Medical Journals were publishing that blood products transmitted Hepatitis Non-A Non-B before I received that product?
4. Why was I never traced in relation to my Hepatitis C status that allowed both a situation to occur where I was left at further risk, my husband was placed at risk and any potential children being at risk? Why has no Tracing and Lookback Programme occurred in the United Kingdom?
5. What are the protocols for informing patients of a terminal illness? Were those protocols adhered to in the context of my situation?
6. Why has there been no acknowledgement associated with what occurred to me in terms of the irretrievable alteration of my life path by Government? Why has it taken so long for this Inquiry to occur and why has neither Government nor the Health Services addressed this issue over many decades?
7. Why have many people who lost significantly in financial terms never received appropriate recompense in relation to those losses?
8. What motivated Government to facilitate the importation of contaminated blood products into the United Kingdom?
9. What can be undertaken to prevent the repetition of these events ever again?

I wish this Inquiry well in relation to its investigation and I earnestly hope that no stone will be left unturned to ascertain the true events that occurred in the context of contamination of both blood and blood products within the United Kingdom.

Statement of Truth:

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

Dated the 1st day of MAY 2019

Signed:_ GRO-B ________________