

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN0381001

Exhibits: WITN0381002-9

Dated: August 2019

## INFECTED BLOOD INQUIRY

### FIRST WRITTEN STATEMENT OF

GRO-B

I, GRO-B will say as follows:-

#### Section 1. Introduction

1. My name is GRO-B I was born on GRO-B and I live at GRO-B GRO-B.

2. I am an only child of South London working class origins with a maternal 'history' of haemophilia, living in its dark shadow and the grief it caused. I have been married to GRO-B for over 50 years and we have two daughters, one of whom has two children. I am somewhat introvert, ageing and retired. I rarely, if ever, feel well and am mentally and physically exhausted especially by the duration and excessive demands of this tragedy.

3. I am one of the haemophilia A English victims and survivors of this tragedy who was infected with Hepatitis C from treatment with contaminated blood/blood products which have had an adverse detrimental impact upon my life.

4. This witness statement has been prepared without the benefit of access to my full medical records.

**Section 2. How infected**

5. I have moderate/mild haemophilia A and I have been given to understand that my Factor VIII levels have apparently increased with age from 4% to 7% when tested recently. Exhibit WITN0381002 is a copy of my letter to the IBI Ref: 11.02.20.5.ibi.1 dated 18.03.18 which includes amongst others the following comment;
6. I respectfully suggest that having been born in GRO-B the period of my life does coincidentally also cover a history of haemophilia treatment in the UK, from 1945 when there was no NHS or 'treatment' through its various forms and 'developments', concerns and warnings etc until the present day. In this respect I have, during the course my lifetime, received various forms of treatment for haemophilia which were available at the time.
7. I recall when there was no treatment other than immobilisation, and 'Quack' type remedies such as the likes of White Horse oil, Kaolin poultices and hot water bottles.
8. I experienced each tiny development in treatment as and when it became available. I have recollections of early forms of treatment based upon snake venom, whole blood transfusions (to which I had a severe anaphylactic type allergic response apparently due to 'anti GMA antibodies'), then packed red cells (with intravenous antihistamine to suppress possibility of reaction), whole plasma, cryoprecipitate, DDAVP and tranexamic acid for less demanding situations.
9. As far as Factor VIII concentrates are concerned, whilst not entirely complete, I have some of my medical records from the Oxford Haemophilia Centre

(OHC) at the Churchill Hospital in Oxford, which includes reference to and notes of my being treated with HYLAND Factor VIII human derived concentrate in 1973, when I was an inpatient of and transferred from Kings College Hospital (KCH) to become an inpatient at the OHC. This is my first recollection of any such treatment with human derived Factor VIII concentrates and I refer to **Exhibit WITN0381003** which is entitled "*Ref 11.02.4.ohc.8*".

10. Whilst I currently have no record in my possession I believe and am in no doubt that following my return to and discharge from the Churchill later in 1973 I was also subsequently treated with human derived Factor VIII on other interim occasions afterwards up to until around the mid-1980's. When alternative, probably heat treated, concentrate Factor VIII treatments became available and were then used.
11. I recall that I was treated with heat treated recombinant products once these became available and as far as I am aware, use of the same has been without consequential problem.
12. For the most part, I have been treated at KCH, where there have been a number of doctors/consultants who have been involved in my haemophilia care and treatment since my early childhood. Those I recall include Dr Peter Flute, Prof Ruben Mibashaum, Dr Henry Hambly, and most recently Prof Roopen Arya. I was also a patient of KCH Institute of Liver Studies and Dental Hospital for a number of years.
13. However, due to the closure of the haemophilia centre and '*withdrawal*' of dental care at KCH, I was transferred to at St Thomas' Hospital (STH), Centre for Haemostasis and Thrombosis (The Haemophilia Reference Centre) in London in 2013. I am still currently registered as a haemophilia patient at STH but no longer for dental care for which I am now registered with a local private practice for routine matters. However, for other '*invasive*' type treatments I would need referring to a specialist hospital unit forming part of or associated with a haemophilia care centre.

14. Furthermore, I have also been a co-care type haemophilia patient at the OHC.

In 1973, I was initially referred there by KCH under the care of Dr Charles Rizza, Dr James Mathews and the surgeon Mr A J Gunning who were the principals involved in my day-to-day inpatient care. Dr Sophie Aroni and Dr Peter Kernoff were also involved in my day-to-day inpatient care. I refer to **Exhibit WITN0381004** in this regard which is "*Ref 11.02.4.ohc.7*".

15. I believe Drs Rizza, Mathews and Aroni were OHC based but that they also conducted wider research projects. I further believe that they also carried out wider projects in relation to co-care and for personal logistical reasons when the principals were Dr P Giangrande, Consultant Haematologist at OHC and Dr David Keeling.

16. I have also been a co-care type haemophilia patient at my local hospital, Milton Keynes University Hospital where I received treatment with recombinant products. I reconnected again in 2018 as a co-care patient under Dr Sarah Davis, Consultant Haematologist. This means that I can attend if I have an emergency or if I need support with any of the home treatment of recombinant products supplied by STH.

17. In relation to the dates on which and the period of time over which I was given infected blood products I refer to my Expression of Interest in providing evidence to the Infected Blood Inquiry form Ref: 11.02.20.5.ibi.6.Rev A dated 06.08.18 which is attached at **Exhibit WITN0381005**.

18. I also refer to **Exhibit WITN0381005** in relation to when and how I found out about my infection.

19. I was not infected as a result of my relationship with another person. However, I note that at a much later date after being diagnosed and once these infections were better understood we informally became aware that these diseases could be transmitted to our partners and others the impact of which were most challenging devastating life and relationship altering circumstances.

20. I am a haemophiliac who was infected by treatment with contaminated blood/blood products with what was initially and for some time afterwards somehow recognised and known as "*Non-A Non-B (NANB) Hepatitis*" that later transpired to being specifically identified as Hepatitis C and in my case Geno Type 1.

DATE OF DIAGNOSIS

21. Having been prompted by overhearing others being asked and thoughts arising with regard to my receiving a formal diagnosis I recall that this question has been raised before. In my case, and as far as I have been able to determine, my date of diagnosis was made at an appointment I had with Dr Charles Rizza at the on 18.06.1991. It was then subsequently discussed between us at an appointment arranged to do so on 10.09.91. In this respect, I wrote to Dr Paul Giangrande on 08.08.2004 with regard to my medical records and specific questions including clarification of the date on which I was formally diagnosed. I confirm that I have had sight of my OHC medical records.

22. However, whilst there are some '*typical*' documents on my file which refer to a diagnosis, there is no clear or specific record on the file of the actual date and means by which I was informed. In addition to this there is no specific record of my GP having been advised in the normal routine manner. Such things have caused me to wonder if my OHC records are as intact and complete as they should be. I sought further advice in regard to this; but to no avail.

23. Following receiving verbal confirmation of my Hepatitis C diagnosis in a meeting with Dr Rizza in 1991, I was in a very confused state of '*uncertainty*' because I was not provided with any information about my infection. Shortly afterwards I actually wrote to ask Dr Rizza if we could meet in order to clarify the implications of my diagnosis.

24. I was not provided with any adequate information about how to manage my Hepatitis C in the beginning. Subsequently and gradually, more and more information became available to me as the enormity of and implications of this tragedy became more evident.

25. I believe that there was information regarding my infection that should have been provided to me earlier than it was. Furthermore, the way in which the diagnosis of Hepatitis C was communicated to me was entirely inadequate. I recall it being told to me in a very cold and casual, almost dismissive manner, as if it did not pose any problem. It felt like I was being told not to worry too much about it because I had already seen my children grow up and would probably die of a more common Haemophilia related episode, such as a brain haemorrhage.

26. I was not given any information about the risks of infecting others when I was diagnosed. I informally came to learn of such a devastating risk a considerable time afterwards.

### **Section 3. Other Infections**

27. I am not sure of the details but I have previously been given to understand that I have in some way or another been infected by either or both Hepatitis A and B and I have been inoculated against for one of them.

28. I understand that there is a chance that I may have also received other infections as a result of being given infected blood products which I have not had the courage to pursue. As far as I am aware, this has not yet been investigated.

29. However, apart from the formal Public Health warning type letter regarding vCJD, I am not aware of having been tested for or diagnosed with any other infection.

### **Section 4. Consent**

30. I believe that I was tested and treated without my knowledge. Whilst it may not have been clear at the time as no such thing was explained to me, I was a Haemophiliac patient in need. I was naïve, innocent and had no real idea about being treated with Factor VIII concentrate actually constituted. As far as I was aware, this was a new treatment without threat and as later referred to in my words to the Archer Inquiry as being '*magic*'. In addition, I put my faith, trust and life into the hands of others as I did before and subsequently still do.
31. I am aware that routine monitoring takes place and informs upon care and treatment. However, I subsequently realised with the benefit of hindsight that as well as being a patient I was also an innocent '*guinea pig*', which was especially true in relation to the '*new*' Factor VIII concentrate. I believe I was tested and treated for the purposes of research. Whilst this wasn't evident to me at the time, I have no doubt that was definitely an aspect of my treatment with Factor VIII concentrate especially as major surgery was involved, which at the time was a very significant '*development*' in care.
32. I believe that it is highly likely that additional research type records were made and kept separately from my medical records. **Exhibit WITN0381004** presents an example of this, albeit perhaps an innocent example, in the form of Dr Peter Kernoff's '*greetings*' type card to me as referred to under Item 4.8.d and APPENDIX item 6.4. I refer to this card in more detail below.
33. As referred to above, as far as I was then or am aware now, there was no such research or experimentation with which I was knowingly involved and I have no such details. However, following my discharge from OHC following surgery there in 1973 I wrote, as a matter of courtesy, to those who had been involved with my treatment and care in order to express my thanks and gratitude for their endeavours on my behalf. In response, I received a personalised card from Dr Peter Kernoff which I treasured and retained.

34. I saw this card as a simple humanitarian and '*emotional*' gesture and not as some form of acknowledgement that I had been used for research or experiment of which I was not aware. It was only sometime afterwards, and as I began to understand the enormity of the situation of the contaminated blood issue, that it occurred to me that I may have been an '*innocent guinea pig*'.

35. I was not advised about or requested to give any form of consent to being treated with Factor VIII concentrate or any subsequent testing for infection.

#### **Section 5. Impact of the Infection**

36. The mental and physical effects of being infected with Hepatitis C were devastating and I refer partly to **Exhibit WITN0381005** in this regard.

37. I struggled previously and do so again now with, and pondered at length upon, how to respond to this process and I concluded that rather than start afresh I depend instead upon some of the wider ranging comments previously submitted to the IBRT both prior to and subsequently in response to the Infected Blood Consultation as they have relevance to this Inquiry. I refer to **Exhibit WITN0381006** which is entitled Ref 11.02.20.1.1 dated 13.04.16, in connection to my impact statement, which I expand upon below.

38. The '*Impact Statement*' of each individual haemophiliac and other bleeding disorder victims and survivors of this tragedy will differ considerably due to the wide ranging and highly complex nature of their experiences, circumstances and the devastating detrimental impact of both the stigma and this tragedy has had upon their lives.

39. However, what the victims and survivors of this tragedy are most likely to have in common are the numerous and significant, physical, psychological and traumatic suffering.

40. I confess that I have not been completely comfortable with sharing in this way. Especially as this is highly sensitive personal information that I would prefer

## ANONYMOUS

not to be in the public domain. However on balance I feel, believe and have concluded that it does, given such circumstances and in summary terms, have some relevance to this process.

41. There is no doubt whatsoever that having Haemophilia, or any other bleeding disease, is a burden which has alone blighted and hindered my own, and probably the lives of others in similar circumstances. To add to this is the fact that as a result of my Haemophilia, I was also infected with Hepatitis C by treatment with contaminated blood/blood products, which has had an enormous additional adverse impact upon my life.

42. The combined effect of such a situation has, for me at least, been a truly devastating and life changing experience. I have been unable to adequately cope or function on a normal daily basis. I have struggled, and continue to do so, with my general well being, to include both my physical and mental health.

43. However whilst my life has been altered it 'goes on', albeit in a less than 'normal' way, based upon a far more isolated withdrawn one step at a time 'day to day' type approach not daring to venture, look or plan ahead as would normally be the case. Instead there is a constant paralysing sense of insecurity, misery, dread, fear of deterioration and prospect of death.

44. The routine and prospect of normal life, enjoyment of and what goes with it has been severely diminished. My personal relationships have been tested and my career and employment disrupted leaving financial insecurity. My insurances have been complicated and I am left with countless problems trying to travel.

45. There is no doubt that the damage has been done and during the course of an unrelenting dark period of time it has been impossible to avoid the anguish, anxiety, stress, depression, fear, traumatic effects and the daunting overwhelming mind clogging thoughts and sleep deprived nights that go with it, from which there has been no respite. Instead, there is a realisation that I have not, and will never be able to fully come to terms with, overcome and

recover from such experiences which are, in one way or another, present on a constant daily basis.

46. This extent of the grief and impact of this burden has been and is immense. It is beyond adequate description. There is not a day that goes by without me also giving thought to wondering about how, thus far, and in some truly astonishing way, I am surviving despite having been injured. I have somehow '*dodged the bullets*' of HIV that have so tragically killed other trusting people who have also been unwitting innocent victims of this tragedy.

47. Haemophilia and bleeding disease sufferers are of course also mindful of the existence and exposure to other such infections as a result of treatment with contaminated blood/blood products. One example is vCJD and the chilling formal public health warning registration letter we received about it. Who knows what, when and how many other such infections there are to challenge us all still further, and reveal themselves in a similar way to Hepatitis C and HIV.

48. There is, of course, a great deal more to Hepatitis C than liver disease alone. Part of this is the impact that such complex things and their side effects have had on normal life and such things must not be disregarded in bringing rightful closure to the victims and survivors of this tragedy; as a matter of urgency and before we all die.

49. In summary terms, I have suffered for years and continue to do so. I feel unwell, physically and mentally tired, have concerns about my capacity, ability, memory, vagueness, procrastination and what has been referred to as '*brain fog*'. I suffer from slowing mental agility, difficulty with mobility and chronic pain due to musculoskeletal conditions, poor sleeping, restless often disturbing brain '*whirring*' nights and I struggle most mornings. Whilst not formally diagnosed I believe that I suffer from Seasonal Affective Disorder (SAD) and a form of Post Traumatic Stress Disorder (PTSD) due to my infection.

## ANONYMOUS

50. My life has long since lost any real spark. I am withdrawn thus somewhat anti-social and I avoid, as far as possible, stressful situations. I dislike planning too far ahead, being reluctant to leave or venture far away from home. I am in day-to-day survival mode rather than living a life and enjoying it which my wife has thankfully great forbearance.

51. As far as mental health related depression, anxiety, stress and the like are concerned, and whilst it did not at the time occur to me, I later realised that being unable to adequately cope and function normally I had suffered what amounts to a complete breakdown in 2000. This occurred primarily due to my infection. I still suffer with my infection and will never fully recover from the same. However, whilst I very rarely if ever feel 'well' for reasons summarised elsewhere in this statement, as far as I am aware there are no other conditions that I suffer from which would have caused such symptoms. I have been significantly and holistically affected by my infection.

52. In addition to Hepatitis C and Haemophilia A, I have a number of other health issues such as Osteoarthritis, Sciatica, lower back problems, Gout, Tendonitis, Hypertension, palpitations, 'dry coughing' type spasms, Prostate, Tinnitus and 'digestive'/IBS type problems. NOT RELEVANT

NOT RELEVANT Some of these problems have caused, and continue to cause chronic pain and discomfort which has both an exhausting and detrimental adverse effect upon my life. These difficulties restrict my walking, mobility and ability to carry out normal everyday activities. Thankfully my wife supports me in relation to the same.

53. As far as I am aware, I have not been formally advised that these physical conditions have been caused or made worse by Hepatitis C.

54. Some while ago, I also discovered that I had, at some unknown point, been infected with Helicobacter Pylori. I underwent surgery in 1973, which included amongst other things a Vagotomy procedure. I have recently learned that this procedure has long since been abandoned. The Vagotomy nerve is of vital

importance to our overall wellbeing which is something that I have not really experienced.

55. I take the opportunity to mention that casual leisure type activities, such as swimming, angling and walking, especially in the countryside or at the seaside beaches and pathways, were once a significant therapeutic part of our life. Due to my health issues I am restricted from participating in such activities and I mourn and greatly miss the loss of the same.

56. As a patient of KCH Haematology and Department of Liver studies I have received monitoring and diagnostic type investigations such as routine monitoring type blood tests, ultra sound scans, endoscopies, fibro scans and liver biopsies. I also received a full course of what was then the '*standard*' form of Interferon/Ribavirin type treatment for my Hepatitis C genotype 1 infection in 2006 which was debilitating and arduous. After 18 months it proved to be unsuccessful which was devastating following which I was invited, agreed to and participated in a formal clinical '*trial*' of similar I/R+TMC435 treatment of the same duration in 2010. This was also debilitating and arduous but remarkably cleared my Hepatitis C genotype 1 virus.

57. As far as I am aware, I did not feel or believe there to have been any untoward difficulties or obstacles in being offered or obtaining treatment for my Hepatitis C infection which I believe was made available in a timely manner as and when it became available, and was considered to be appropriate.

58. The mental and physical effects of the treatments I have received have been devastating. However, as I preferred the possibility of being free from infection and did not want to suffer or die because of my Hepatitis C, it seemed to me there was little realistic choice available other than enduring and tolerating these procedures and treatments.

## ANONYMOUS

59. However an aspect of receiving the treatments I endured involved being economic with the truth by overcoming the temptation to be more honest about how I actually felt especially during the two courses of treatment as I was afraid that if I spoke out the treatments may have been discontinued.
60. I cannot be sure about how my infected status impacted upon my treatment, medical and dental care. However, on reflection, I did wonder because a surgical procedure I was due to undergo was unduly delayed. Whilst I did not want to make any fuss at the time, when I enquired about it after a long period I was advised that my records and arrangements for the surgery had gone astray. This surgery actually took place some considerable time after it was originally scheduled.
61. Furthermore, my long term dental care at KCH ended and was transferred to STH where it also ceased shortly afterwards. Since then I have had to become a local private practice patient, but only for routine matters as they are unable to accommodate complex dental issues that would require referral to a hospital for associated Haemophilia and dental co-care purposes.
62. Due to the stigma and derogatory comments voiced about the infected and affected by the contaminated blood tragedy it was a version of the '*elephant in the room*'. It was always something not to be '*out*' about, thus in my case very few people knew. Some of those who knew had guessed as they knew I was a Haemophiliac. I never told my parents as I believed that they had already suffered enough.
63. I left school and started work in 1960, when I was aged 15, which was before this tragedy became apparent. I was continually employed for 42 years before recession forced my redundancy in 1992. I had become very unwell and I suffered a complete breakdown. I remained so unwell that I was unable to continue with my career, as a consequence of which it prematurely came to an end in 2000 when I was aged 55. I endured such challenging circumstances and upon reflection I believe that these contributed to my survival.

64. The financial effects of being infected with Hepatitis C were devastating due to being unwell. I was unable to continue working which meant there was an associated loss of earnings and reliance upon benefits between 2000 and 2010. There was an adverse detrimental impact upon us then and now, in our retirement years.

65. Please see **WITN0381008** for my original manuscript version of my statement.

66. The impact of my infection was devastating to my family. Such matters are extremely sensitive and I prefer to avoid any further comment in this regard.

#### **Section 6. Treatment/care/support**

67. As far as treatment for Hepatitis C is concerned I believe that it has, in my case, been forthcoming as and when it became available. However, whilst I have received mental health care, it was of a general nature rather than specific infected blood related purpose. I was not offered any specific mental health care until it was offered by the Inquiry. Despite the obvious need, as far as I am aware, no mental support has been offered to the infected and affected before.

68. I am aware that as a part of the more recently introduced contaminated blood related reforms, mental health was acknowledged and recognised as being closely associated with and very much part of the contaminated blood tragedy for which such support was made available. I have not pursued the same.

69. Shortly after my Haemophilia care was transferred to STH in 2013, I made enquiries with regard to the availability of mental health care support. I had appointments with a health psychologist associated with the department. However, as that facility was more closely associated with adolescent care and CBT, I concluded that having received course of CBT previously I did not think that more of the same would be helpful to me. I also felt it would cause

unwelcome stress due to my travelling to London from my home in GRO-B

GRO-B

70. In this respect, and as best as I am able to recall, the fundamental reason for seeking support was that in around 1989 it became clear that I was suffering from mental health issues for which I was referred to a psychiatrist based at a local NHS mental health facility from whom, and together with my GP, I received support and treatment over a long period of time. I mainly, as I recall, received treatment in the form of various types of medication which did not prove to be very effective.

71. In around 1999 and 2000 I became very unwell and was referred again and received various forms of treatment for mental health related issues from the NHS hospital specialist psychiatric unit. I also saw other private organisations involved with mental health care and received medication, although this was again unsuccessful. I received various forms of therapy including relaxation techniques, CBT and group analytical psychotherapy sessions. It was then, for me, prematurely terminated for financial/service 'cuts' reasons in 2004. Whilst I believe there has been some need, I have not involved myself with any other treatment since, relying instead upon my experiences and instincts to cope at times albeit 'painfully' so.

72. I am in no doubt whatsoever that the mental health issues from which I have been suffering with, and still suffer from, are significantly and substantially attributable to my being infected with contaminated blood/blood products. Furthermore, whilst having not been specifically diagnosed, I am in no doubt whatsoever that I also suffer from SAD and based upon what relatively little I know of it, I also believe that my Hepatitis C infection and the consequences of it have also had a PTSD type detrimental impact upon me.

73. At the end of my Hepatitis C treatment in 2016 I wrote the following and I take this opportunity to refer once again to the matter of holistic treatment as follows:

## ANONYMOUS

*'However I also feel compelled and take this opportunity to share some further cathartic patient feedback type thoughts and comments which I offer with utmost good will and intention that I hope and trust may be of some interest in particular with regard to patient mental health considerations arising from such and similar circumstances'.*

74. I am of course grateful for the treatment and support that I have been dependent upon and received from the NHS and its members of staff throughout my life. However, I am well aware and realise that funding, costs and for that matter all other aspects of the NHS are unfortunately under considerable pressure.

75. Despite this, I believe that mental health considerations and provisions are of significant importance to the holistic care of patients involved with other serious, long term/life threatening ailments. I believe that holistic care should ideally at least be discussed with patients, and if appropriate be made readily available and offered in support as a parallel part of their overall care, treatment and wellbeing.

76. I do not wish to appear in any way melodramatic but I am in no doubt whatsoever that having Haemophilia is a burden which has alone blighted and hindered my own, and probably the lives of others in similar circumstances. Having also been infected with Hepatitis C has had an additional adverse detrimental impact upon my life. The combined effect of such a situation has, for me at least, been a truly life changing experience which has had a devastating effect on my general wellbeing, physical health psychological and mental health. I continue to struggle and have been unable to adequately cope and function on a normal daily basis.

77. I also take the opportunity to mention one other particularly significant change that arises as a result of changes in Haemophilia care at KCH. It marks the end of an era for what has been a *'lifelong'* period of time during which, and in various ways, I have continuously been a patient of KCH since early childhood. I have traversed circumstances that have presented significant

personal loss to me and I had built up strong emotional connections associated with KCH.

78. I believe that the conditions, from which we suffer, such as Haemophilia, "HIV" and Hepatitis C, together with the resultant mental health problems, are relatively 'invisible' and tend to be kept that way. This presents additional and harmful challenges for those who are infected.

#### **Section 7. Financial Assistance**

79. As far as the initial Caxton/Skipton Fund arrangements are concerned I am unable to accurately recall how, but as far as I can remember I think I was first advised by my Haemophilia Centre, following which I made such enquiries and subsequently received payment from the Caxton /Skipton Fund followed by EIBSS as referred to below and in **Exhibit WITN0381005**.

80. I received an Ex Gratia payment of £20,000 from the Caxton/Skipton Fund on 17.09.04. I also received a number of annual winter fuel payments from the Caxton/Skipton Fund. Furthermore, I received monthly payments of £252.50 between April 2017 and October 2017, together with an annual payment of £3,030.

81. In November 2017 the EIBSS took over responsibility for, and became the new scheme administrator. In March 2018 I received a Special Category Mechanism (SCM) payment of £4797.50, back dated for the period between October 2017 and March 2018 after which SCM payments of £1,500 per month and £18,000 per annum commenced. I do not currently consider it to be applicable in my case and have not applied for, nor do I receive EIBSS 'Discretionary Payments' which, and in any event, I consider to be demeaning and avoidable by other more civilised means.

82. Given such circumstances applying for financial assistance of this sort is an appalling thing to have to even contemplate, let alone actually do. However, despite the fact that I don't think people should be made to apply and the

application procedure not being without its demands and challenges; my applications to both the Caxton/Skipton Fund and EIBSS were straightforward.

83. I found it very difficult to give the appropriate consideration to the financial assistance and actually carrying out the application process. The funds themselves could have been avoided if due just closure and compensation were forthcoming; both of which I consider necessary.

#### **Section 8. Other Issues**

84. Unlike many of the infected and affected who have already, and so tragically, passed away I am remarkably by some form of miracle or another still alive. Whilst I may prefer it to be otherwise and there be no such need, I nevertheless feel an obligation to contribute to this Inquiry as best I can. In this respect, despite the utmost excruciating challenge and anguish of doing so, this response is made with an overwhelming sense of moral obligation towards victims and survivors who have passed away, have fading or no longer have the memory, will, strength or voice to register the utter despair, discontent, dismay, dissatisfaction and disappointment with this most shameful tragedy.

85. I welcome and acknowledge that Collins Law and no doubt the Inquiry itself are in a position to be able to offer help to individuals such as myself in their preparation of Rule 9 evidence which is greatly appreciated. Whilst constantly endeavouring to avoid '*living in the past*' with this, it is nigh on impossible not to due to such painful recollections staying indelibly with us and leaving their ugly mark, especially in circumstances like this. It is probably a case of living in fear of your life can be no life at all and living with the appalling horror of knowing that something has irretrievably been deliberately put inside of your body that is doing harm and killing you is a burden that is far beyond belief and description.

86. In this respect whilst, like others, I have my story and welcome and appreciate the opportunity offered to give evidence and tell it and even if I had the capacity to do so I consider the majority of it to be private and personal in which case I prefer and do not necessarily wish to reveal it to others especially in such an open and public way. However and as I have previously referred to elsewhere despite the stress, difficulty and anguish of doing so because my capacity, memory and mental agility are what they used to be I prefer instead to consider the Rule 9 questions before trying to respond to them. I prefer to do so in writing rather than attempting the same face to face, 'off the cuff' and verbally to someone that I do not know, only for them to then write responses for me sign off; a process with which I am neither familiar with nor comfortable.

87. Whilst I recognise that we have our part to play in this Inquiry it is not so much the already 'exhausted' infected and affected and their obvious plight that requires detailed scrutiny, it is instead those involved, responsible and accountable together with the relevant information, circumstances and reasons. The Infected Blood Inquiry has had an enormous burden of responsibility and trust placed upon it, especially by the infected and affected persons who have been deliberately denied due justice and closure for far too long. I acknowledge that the Inquiry's task is a considerable one given that the moral case has been flogged to death.

88. This includes, for example, the fact that it has not yet been made clear to the Inquiry who was involved, responsible for and 'signed' the causes of this tragedy off. Were these decisions made knowing that these blood/blood products carried infections which would have such devastating consequences? If the answer is no then this surely demonstrates a serious lack of due care, diligence and neglect for which appropriate formal action would need to be taken. If the answer is yes, this surely demonstrates that a serious crime against those infected and affected was committed, for which appropriate formal action would need to be taken as a matter of urgency and as part of the closure required.

89. Despite this, my own previous representations and references to the matter and the albeit belated Andy Burnham valedictory like statement that he was in possession of evidence of a crime having been committed and his threat to involve the police which was made so openly and publically in the House, it is remarkable that, as far as I am aware, there has been no commencement of any formal criminal investigation into this issue. No explanation has been forthcoming as to why this has been the case and as such I have recently made further representations to the Inquiry in this regard.
90. It would appear (and I acknowledge that) Andy Burnham's statement and threat contributed towards the Government's decision to establish this long overdue Inquiry. Therefore, the Inquiry, together with other authorities including the police, must surely give urgent consideration to investigating and determining whether or not there have been any crimes committed. Such investigations must not be delayed and instead take place in parallel alongside this Inquiry. I urgent and request that this takes place at the earliest possible juncture to ensure that just closure is reached for those who have been infected and affected by this tragedy.
91. In the meantime, whilst I am no expert, it nevertheless occurs to me that such crimes might include such things as perverting the course of justice due to the prolonged and deliberate lack of cooperation and '*cover up*' by Government. Other authorities and parties have become involved due to their "*silence*", for example perhaps by deliberately ignoring the Inquiry's formal '*Do Not Destroy*' Notices. It is incomprehensible that Simon Steven was allowed to continue in his post and a full investigation should be undertaken as to why this was allowed to happen.
92. Other matters which need urgent attention include withholding and/or failing to provide '*missing*' information, destruction of Government and medical records, causing serious injury and/or death due to treatment with contaminated blood/blood products. All of these matters need to be comprehensively resolved by carrying out necessary investigations and instigating formal proceedings as a matter of extreme urgency without further ado.

LEGAL ACTION

93. With utmost respect to the legal firms involved with this tragedy, on behalf of the infected and affected I feel compelled to mention that it has long since been and is still abundantly clear that this monumental tragedy has had the most devastating and detrimental impact upon the infected and affected who have been placed at the focal point of this Inquiry. There has been no appropriate comprehensive compensation or closure due to the deliberate and unduly prolonged Government intransigence and shameful attitude towards the infected and affected.
94. These have long since been and are the most powerful and compelling circumstances about which the Government can and will hopefully act compassionately, honourably and urgently. Such a response would avoid the prospect of legal action being required.
95. The infected and affected require financial compensation and closure without further ado. The infected and affected were, for a considerable number of years prior to the Public Inquiry, deliberately treated in the most shameful and deplorable way by successive Governments. Information has been withheld and they have been taken advantage of because they were a relatively isolated group of lay persons who lacked cohesion and therefore struggled to come together to make their case.
96. An example of this was borne out by the revelations contained in the shocking Margaret Thatcher letter. I also wanted to include the John Major Lottery letter as an example, because this was subsequently shown to have been perhaps deliberately so shamefully misrepresented to the Inquiry. However, that mistreatment and isolation of victims has at long last been somewhat altered by the commencement of the Inquiry into this tragedy. Those attending the opening of the Inquiry were linked and united in various ways by the Inquiry in its quest for truth, justice and closure. Hopefully the Inquiry can achieve these objectives without recourse to legal action.

97. In the meantime the eventual outcome of the Inquiry may, given what is already irrefutable and compelling, make an even more compelling case for compensation and the part it has in bringing about comprehensive and just closure for the infected and affected. However, and as far as I currently understand it, assuming that the outcome of the Inquiry does result in an even more compelling case for compensation the Government is not currently obliged to 'automatically' provide it and may instead choose to deliberately prolong and/or ignore any such call again as it has done in the past.

98. Such a situation gives rise to the most daunting prospect of further on going legal action that may need to be confronted. I hope and believe that this should be avoided by the Government. Perhaps by being prompted by the Inquiry sooner rather than later, at long last, the Government will do the right and honourable thing by providing compensation in the not too distant future together with a comment such as: *'As I am sure that the Inquiry appreciates this is all contributing more towards what is an already a highly stressful situation in which case I implore the Inquiry to do all that it possibly can to reduce the unwelcome effect such circumstances are having upon me and I suspect others like me feeling as I do ever more daunted, 'unwell', overly stressed and exhausted by such highly demanding and challenging circumstances.'*

99. However I, albeit naively, still hope for and have some expectation that all aspects of this tragedy could and will be comprehensively dealt with and concluded by the Inquiry and the Government, ideally without the need for any separate legal action.

THE HAEMOPHILIA SOCIETY AND MEMBERS OF THE APPG

100. As I consider it to be of relevance I take this opportunity to mention that I have been a member of the Haemophilia Society ("*the Society*") for many years during which time I have often written to the Society. During the prolonged period of time that the infected blood/blood products issue has

## ANONYMOUS

been in our midst with regard to the Society taking meaningful action including the need for legal representation so as to fully represent and support their members and others affected by this tragedy which, and as I consider to be evidenced by the current state of affairs has not, in my opinion, been adequately forthcoming.

101. I have unfortunately felt compelled to write to the Society more recently in order to express in particular my concern and dissatisfaction arising from the misleading nature of the reference made early in the Inquiry process in relation to the John Major Lottery Letter and their apparent refusal to comply with the Inquiries Section 21 Notice to provide documentation. In addition and more recently, I have written again to the Society with regard to their decision to terminate their involvement with Malcolmson Law and appointment of Eversheds Sutherland, who I understand also represent various other parties, including for example Government Departments such as the DOH, DWP and Treasury Solicitor as well as pharmaceutical firms, all of whom are inextricably involved with infected blood/blood products issues, the Infected Blood Inquiry and its scrutiny of them. I have shared my concerns with the Inquiry and requested that they be taken into due consideration and account as part of its investigations and if appropriate take formal action as appears to be necessary and required.

102. I have made reference elsewhere to the Haemophilia Society's somewhat privileged and close access to the APPG and due to my cynical tendencies and concerns which are further bolstered by knowing that the Society is deeply involved with being investigated by the Inquiry I wonder what their real motivation came from such a privileged '*insider*' position. I make similar comments in relation to their attempts to change their name which I objected to for obvious reasons.

103. Furthermore and in a similar vein it has also come to my attention recently that in addition to the likes of Clarke, Major, Fowler and the like, Virginia Bottomley is amongst those likely to be called upon by the Inquiry to give evidence and I note that her husband Sir Peter Bottomley was also

## ANONYMOUS

involved with the APPG. Whilst no doubt his intentions were good, he would have also had an opportunity to keep an eye on things from such a privileged '*insider*' position which in instances such as this is are for me at least a cause of some concern worthy of clarification.

104. I would like to take this opportunity to exhibit at **WITN0381009** some of my correspondence with KCH in regards to my medical records.

### Anonymity

I wish to remain anonymous.

I do not wish to provide oral evidence to the inquiry.

ANONYMOUS

**Statement of Truth**

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

Signed.

GRO-B

Dated.....

08.08.2019