Witness Name: GRO-B
Statement No: WITN 1379001
Exhibits: WITN 1379002 - 4
Dated: December 2018

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 and live with my wife at GRO-B We do not have children. I suffer from Hepatitis C and I am chronically ill. My wife is also in poor health. We look after and support each other to the best of our abilities.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

3. I obtained my medical records in 2017 from solicitors who had requested these on a previous occasion. I had been told previously by Manchester Royal Infirmary (MRI) that my records were destroyed approximately 8 years after my last attendance there. At the time of my request they did acknowledge that my records should have been kept due to my haemophilia and my having

received blood products but that they had been destroyed in error due to a failure in the Trust's processes.

Section 2. How Infected

4. I was adopted at 6 weeks old and diagnosed with severe Haemophilia A at 18 months. It would appear from a letter in my records dated 21 January 1957 that I was already considered "damaged goods" even at this early age as the Doctor, when remarking on my condition, concluded that "it is unfortunate that he is an adopted child but there is nothing can be done about that"

5. I was educated at home from the age of 5 until 7 and then attended a special school for children with disabilities until age 11. During this time my haemophilia medical needs were overseen by the Manchester Royal Infirmary ("M.R.I") and included a number of inpatient stays over the years. The treatment given for bleeding episodes of varying severity was by infusions of fresh frozen plasma or cryoprecipitate.

6. From 1966 until 1972 I attended Lord Mayor Treloars Boarding School for the handicapped, near Alton, Hampshire. During term time I was treated initially with fresh frozen plasma and then from 1970 with Cryoprecipitate. There is a notation in the UKHCDO database records which may suggests a blood sample taken in December 1969 was sent to Dr Craske for "Research" at an unknown Centre. I refer to exhibit WITN 1379002.

7. After leaving Treloars School I attended 6th Form College for one year and then gained full time employment at a local firm as an Accounts Clerk where I remained fro 2 years before joining the Civil Service in 1975 as a Clerical Assistant

8. During this time I continued to attend M.R.I , occasionally as an in patient, again with varying bleeding episodes, and was treated with Cryoprecipitate.

9. On 12.4.78, aged GRO-B, I commenced home treatment Factor 8 Therapy Concentrate. At no point, either verbally, in writing or in my medical notes was there any mention of any risk associated with this new medicinal product.

10. From my records, it appears that I received my last treatment of non-heat treated Factor 8 on 31.12.84.

Section 3. Other Infections

11. On 22.11.2001, again without any prior notice, I received a letter in the post informing me that I had potentially been exposed to vCJD which meant that I was classified as a 1% Public Health risk. I was told that I had to inform all relevant medical professionals I had contact with which I duly did.

12. I felt at the time that it was a case of "you may have something else as well, just deal with it".

Section 4. Consent

13. On 14.2.85 I was tested for HTLV 3 Antibody, without my knowledge or consent.

14. On 19.6.85 I was a consenting participant as a Factor 8 Deficiency Substrate Donor using Plasmapheresis, where it is documented that a second HIV test was conducted, followed by further HIV tests on 20.11.85, 8.5.86 and 20.8.86, all without my knowledge or consent. The results were, thankfully, negative but their existence and the results were withheld. Some of these tests were requested in association with particular batch numbers of Factor 8 treatment which I had recently taken or was in the process of taking. I refer to exhibit WITN 1379003.

15. I was again tested, without my knowledge or consent, on 1.4.87, and, following this test, without warning, I received a letter on 21.4.87 in the post from the Haemophilia Coordinator informing me that the results of my "repeat" blood tests for HTLV 3 AIDS were Negative. I refer to the Exhibit WITN 1379004.

16. I was initially shocked at this revelation but ultimately relieved, however, I then had the unenviable task of disclosing this to my future wife and my employer. It also seems that, unbeknown to me, my GP received a letter stating that I was HIV negative and there was also a notation regarding the condition of my liver stating that "MY liver, spleen and nodes were not palpable".

17. My wife and I got married on GRO-B and we bought a flat, with the assistance of a mortgage, as we were both working full time.

18. As I was due to attend what I believed a routine check up at the M.R.I,we cut our honeymoon short. My wife and I attended the Clinic together where we duly informed them of our newly married status and change of address. Unbeknownst to us at the time I was again tested for HIV and the result (also negative) was again withheld. As far as I am aware this was my last HIV test.

19. In 1990 my wife and I took our first, and last, long holiday abroad. Unfortunately my wife took ill with the legacy being a debilitating illness which continued, with a slow deterioration, to the present day and as a result she had to give up work.

20. By 1992 she had developed agoraphobia and anxiety which remains to date. It was at this time that the first suggestion that Hepatitis C was a problem began to circulate and I can only speculate that this had a negative impact on her health, with the threat of HIV having only recently passed and which had been a perpetual source of worry.

21. It was about this time, due to the poor state of my wife's health, that I stopped attending the M.R.I as it was a round trip of more than 80 miles. An arrangement was made with my GP to oversee my requirements on behalf of the M.R.I although I recall that they were not entirely happy with this.

22. It would seem that in or about August 1994 my GP was informed by a letter dated 30.8.94 by the M.R.I that haemophiliacs had a 50% chance of having being infected with Hepatitis C and that a test should be considered in case of an elevated LFT result .They considered it likely that the test would be

positive. I was not told about this letter. However I would have been reluctant to go ahead with any investigations at that moment in time, that being my choice and a matter between myself and the MRI. My GP was aware of my thoughts on this.

23. By February 1994 my health started to fail and my haemophilia bleeding episodes suddenly worsened which exacerbated the arthritic problems in my joints. The burden of this, alongside the stress and worry I felt concerning my wife's health, meant that I had to leave my job in the Civil Service, taking early retirement with a small Civil Service pension. I had not at the time made any connection to the fact that my overall health had deteriorated as a result maybe of having acquired Hepatitis C.

24. By 1999 the M.R.I became quite insistent that I be tested for Hepatitis C. I was initially reluctant to proceed, but eventually agreed to take the test. In November 1999 a sample was taken by my new GP.

25. The result was, as I had by now expected, positive. I decided that, I would pursue a Natural Health/Alternative Medicine regime and adopted a healthier lifestyle. This has paid dividends over time, but was quite expensive.

Section 5. Impact of the Infection

26. By 1994 as I could no longer manage the stairs in our first floor flat my wife and I made the difficult (and worrying) decision to move to a rarely available one bedroom bungalow.. It was in a poor state of repair but was at a price we could afford. We felt that this was the only choice that we had, even though such a move was arduous and distressing.

27. With no life insurance available to me, we took on an extended, unprotected mortgage and just hoped that it would be ok but this hope proved unfounded in ways we were yet to realise.

28. At this time my wife was virtually housebound and we were quite far away from the local shops and facilities I started to worry as to how we would

manage should I become too ill to drive, however, another bungalow in a nearby village become available. Our financial situation was not good and, having never asked for help before, I reluctantly decided to approach my adoptive parents for some financial assistance with a top up mortgage.

29. Unfortunately the response was that they were financially committed to my sister (also adopted). I recall that they didn't think we needed anything and that in any event that the Hepatitis C diagnosis was "nothing to worry about" as I would "just be tired and go yellow". I was too dismayed and disheartened to pursue the matter any further.

30. At that point perhaps I should have noticed their disinterest in our situation. I got the impression that they felt that the State/Authorities should be responsible for any financial support so I let the matter drop.

31. In hindsight (and without realising), from the time of my diagnosis, my wife and I became increasingly introvert, unsociable and isolated. I believe that our way of dealing with the new health threat was to try and shut ourselves down. This caused a number of issues with some members of my family. Also my future request for financial assistance which in any event was refused, caused resentment on their part and estrangement, subsequently they moved away from the area without disclosing their whereabouts, and as my wife's family live 100 miles away we have no support.

Section 6. Treatment/ care/ support

32. The rollout of Recombinant Factor 8 treatment began in 2004 but due to the cost and age restrictions (it was more expensive and I was over 40) the old treatment was, as the M.R.I put it, "too expensive to waste". I did not commence the old treatment until July 2005

33. It was around this time that the M.R.I became increasingly concerned that I had not been overseen medically by their Haemophilia Centre and eventually an arrangement was made for me to be seen at my local hospital in Blackpool by the Haematologist there. (Over the many years prior to that my Factor 8

had either ben delivered to my local hospital or it was delivered to me from the M.R.I by private courier which I paid for.)

34. By late 2006 the M.R.I had decided that this arrangement was not suitable, citing the high cost of my treatment which need to be monitored. By their estimate it was costing about £80,000 per year. I do not believe that this was the case for me as by this time they had started to "ration" the amount of Factor 8 they provided me with, presumably to encourage (or force) me to attend Clinic.

35. As a consequence of this I too rationed my Factor 8 to the extent that some bleeds were left untreated until I could put it off no longer which undoubtedly was to the detriment of my condition overall. My estimate of my actual "cost" to them was less than 25% of that figure as I was using much less treatment than I ever had before.

36. I felt that, due to the extenuating circumstances and the fact that I was unable, rather than unwilling, to attend Clinic, their attitude was uncaring and at the end of the day their own requirements took precedence over any difficulties I may have. As a result, I decided to write to (now the late) Lord Morris of Manchester to highlight my situation and was pleased to receive a supportive letter from his office

37. Matters then came to a head when the M.R.I wrote to me stating that if I was not able to attend Clinic they were not prepared to continue to provide me with further supplies of Factor 8. Having received this ultimatum (being a severe haemophiliac) I was immediately forced to try and find a way to resolve this potential catastrophe

38. I had not realised that there was a Haemophilia Centre, comparatively close to where I was living, at the Royal Liverpool Hospital, and it was only by chance that I decided to contact them and make enquiries. To my immense relief they agreed to take me on as a patient immediately, and my GP referred me straight away (although she seemed sceptical that M.R.I would see through their threat to stop providing me with treatment. I however, knew differently). M.R.I could not resist writing to my new Haemophilia Centre

informing them that I had the potential to be a difficult patient and that they should bear this in mind when considering me for their care.

39. I have always resented this unwarranted character assassination, particularly of someone they had never met and which may have led to a difficult future relationship with the staff. Fortunately for me, however, I have received nothing but consideration, kindness and excellent treatment from this Centre and I am still under their care.

40. On 14 January 2008 I was offered the latest therapy available at the time for treating Hepatitis C. This was a 48 week course of Pegylated Interferon injections and Ribarvin tablets which only had a 50% chance of being successful in clearing the virus.

41. The treatment was gruelling and caused considerable side effects which I still suffer from to this day. My monitoring results initially showed good signs and my consultant was cautiously optimistic but the virus returned within 3 months of me completing the treatment much to the consternation of my Haematology Consultant as I was the first (but not the last) to relapse.

42. It was a severe blow to both myself and my wife and it took us some time to come to terms with the situation. My physical recovery was even slower and I never returned to my pre-treatment condition I had been in prior to treatment. No other therapies were available to me at that time.

43. In June 2016 I was offered the opportunity to undergo a second round of the latest Direct Acting Antiviral Treatment as my Fibroscan level and Genotpye fell into the category of Compensated Cirrhosis. This was a 24 week course and the side effects I had experienced with previous treatment resurfaced and remain (in lesser form) to this date. Thankfully this time the virus was suppressed but I still need to be monitored.

44. I have only received support from specialist nurses who have treated me but have not received any specific counselling or psychological support and probably have not been offered these services as the Doctors, Nurses and my GP were aware that I wanted to handle it myself

Section 7. Financial Assistance

45. In 2003 my local council got in touch to ask if I was aware that my wife may be eligible to apply for Carers Allowance as she had been looking after me for many years despite her own poor health. There was, at that time, no other outside help, either offered or available. She did apply and her claim was granted and continues to the present day as I cannot manage or cope without her assistance in many aspects of my life and should she predecease me I would have to apply for help from the State if indeed I was eligible

46. My wife has been in receipt of DLA Low Rate Mobility Allowance since about February 1998 and from October 2005 has also been in receipt of the Low Care Allowance. She is currently awaiting an invitation to claim the Personal Independence Payment (PIP). Unfortunately because of the changes to the State Pension age, my wife (currently 60) will not receive hers until she is 66, in some 6 years time.

47. In 2004 I was surprised and pleased to receive an ex-gracia payment of £20,000 from the Skipton Fund. As I had, by this time, been unable to work for 10 years, the injection of cash helped to pay some money off the mortgage, consolidate some unavoidable debt and, replace some vital household items and, finally complete some long awaited home renovations. I also thought it advisable to invest in a Funeral Plan but in effect the money was used up in essential requirements almost immediately.

48. In 2013 I was informed that my Invalidity Benefit entitlement was due to come to an end and that it would be replaced with a new Contributory Employment Support Allowance and that I would have to submit a new claim. This caused me some concern but after struggling through the required paperwork and gathering supporting evidence from my GP and Consultant, I was granted the benefit for the foreseeable future with no need for review.

49. It was also in 2013 that the Caxton Foundation ("Caxton")came into being and as a result of my low income I became eligible for a monthly top up

allowance. I was also entitled to apply for discretionary grants, however, I did not feel it was right to apply for any grant money to improve a house I did not want to remain living in.

50. In 2015 I finally manged to sell the bungalow at a significantly reduced price as it was still not up to an acceptable standard. The property market had changed considerably and we could only find one property which was suitable (in the right location near to local facilities) but it was a small cottage with stairs and yet again it was beyond our means despite extending the mortgage for 14 years – (again without protection.)

51. In the end my mother in law was adamant that we take a sizable chunk of her life savings to cover the shortfall in the new mortgage arrangements. She, more than anyone else had been privy to all the difficulties we had gone through over the years and was absolutely determined that we accept her help.

52. We agreed reluctantly, feeling that there was no other way but have always regretted doing so. We then sought help from the Caxton Foundation ('Caxton') as we had been made aware that grants were available to assist with moving costs and fitting the necessary disabled adaptations.

53. This all went very smoothly and the Caxton staff could not have been more accommodating and ensured that all the required fees and bills were paid and a stair lift fitted. The only discomforting part was having to explain to the solicitor and estate agent that they would have to wait to be paid as the money was being provided by a charity. I have to say that no one made us feel small and they were aware of our predicament but I still felt like a charity case.

54. The effort of moving took its toll physically, mentally and emotionally and neither my wife nor I have ever really recovered from it but we are happy in our new home and felt more secure at last.

55. Prior to undergoing the treatment for Hepatitis C, curious as to what other treatments were on offer, I contacted the Haemophilia Society who, having

answered my queries, also suggested that I contact the Skipton Fund to claim a Stage 2 payment. I duly completed the required forms but was refused on what I considered to be unsatisfactory grounds. My subsequent appeal was disregarded in an equally contradictory manner. I corresponded with the Fund over a lengthy period of time without satisfaction and have provided all the relevant material to my legal representatives for perusal by the Inquiry Team should it be required.

56. In 2017 I was notified that my DLA High Rate Mobility, Middle Rate Care, obtained with some difficulties ,was due for review, so I would have to apply for PIP instead. Having completed the forms (again with great difficulty) and obtaining supporting evidence from my Haemophilia Nurse and GP, I then had to undergo a home visit from an Assessor. Unfortunately it appears that she had not had any dealings with Haemophiliacs, knowledge of Hepatitis C, its treatment legacy or severe arthritis/hemarthropathy. I had a knee bleed at the time and she expected me to perform some exercises and I refused.

57. The huge amount of evidence I had submitted must also have been disregarded somewhere in the process because when I received the new award notice, to my shock, the mobility portion (which I had been in receipt of for 45 years) was downgraded to Standard Rate and the Care portion classed as the Standard Rate.

58. I then went through the process of Mandatory Reconsideration with the help of my local Welfare Rights team, GP, Hospital and especially my MP, my award was thankfully reinstated to Enhanced Mobility, and the Care remained the same.

59. In April 2018, I was surprised to learn (via the Haemophilia Society) that the DWP intended to reconsider PIP awards for some haemophiliacs with haemarthropathy and was amazed to find that (after some scrutiny) my Care portion had been increased to the Enhanced Rate and that my next review had been extended from two years to the maximum 10 years.

60. In October 2017 there was a change in policy regarding the support schemes in England which were to be replaced by the NHSBSA. I was reassessed by this new organisation and awarded a regular top up income and in July 2018 that award was increased but this is still classed as discretionary.

61. I am currently in receipt of the NHS Health Costs Full Exemption Certificate – HC1 which I have been entitled to for a number of years.

62. Following this the new Special Category Mechanism Scheme ('SCM Scheme') came into force and, although I was reluctant to try for it after my experience with the Skipton Fund, I applied with the assistance of my Haemophilia Consultant. I was extremely surprised that I qualified for the new payment award, presumably having met the criteria of being ill enough on this occasion. However, I am unaware as to how long this form of support will continue so I am not regarding it as a secure form of income at this time.

63. I should state at this point that it has always been an ongoing worry of mine how my wife would cope and manage, financially and otherwise, in the event of my death, This area of concern, I believe remains unresolved and it would be a relief if it was addressed satisfactorily.

64. I have only received support from specialist nurses who have treated me but have not received any specific counselling or psychological support and probably have not been offered these services as the Doctors, Nurses and my GP were aware that I wanted to handle it myself

65. To conclude, I found that compiling this statement, with the help of my wife, an ordeal on many levels. Reliving past events and memories brought back feelings and recollections of times myself and m wife would rather forget, however, since watching the Inquiry preliminary hearings, via the Inquiry website, we have realised, having heard others speak, that we are not alone. Although we are in some ways dreading the Inquiry proper, not knowing what is yet to be revealed, we are committed to following it through to its conclusion all being well as we feel the time for truth and justice to prevail is long overdue.

Anonymity, disclosure and redaction

I do not want to give oral evidence and I am seeking anonymity and would like my Statement redacted before publication. However, I understand this statement will be published and disclosed as part of the inquiry

Statement of Truth

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

Signed……. GRO-B ……………………..

Date. 7/1/2019 ……December 2018

Medical Chronology

(This summary is not exhaustive but sets out key points in the records relevant to the Statement)

14/02/1985	HTLV-3 Antibody test- negative test result (First HIV test- not informed of the test being taken or the result)
18/06/1985	HTLV-3 Antibody test- negative test result(Second HIV test not informed of the test or result)
19/06/1985	Blood sample taken- no notification of test being taken and result. (noted that previous specimen 04/06/1979 tested immune to Hep B)
25/06/1985	Letter from consultant (R. Wenseey) –(Third Anti HTLV3 antibody test- result negative. Not informed of the test or result)
20/11/1985	Lymphadenopathy associated virus Antibody- negative test result. (not notified of this test or result.)
08/05/1986	Lymphadenopathy associated virus Antibody- negative test result (batch KOATE- 50P114- Treated as an out patient at MRI on 8.5.86- LAV antibody(not informed of the test or result)
20/08/1986	HTLV-III ab test taken- result negative (Not informed of test or result)
01/04/1987	HTLV-III ab test taken (not informed) – negative result - received different batch/product HAEMOFIL- 860726A. 9 not informed of test.
21/04/1987	Letter from Haemophilia Centre of the MRI regarding HTLV-III testing- Test results were negative.
13/09/1988	HTLV-III test – result negative (not informed of test or result)

Virology Results

14/02/1985	HTLV-3 Antibody test- negative test result (First HIV test- not informed of the test being taken or the result)
18/06/1985	HTLV-3 Antibody test- negative test result(Second HIV test not informed of the test or result)

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