

Witness Name: GRO-B

Statement No: WITN1470001

Exhibits: WITN1470002-017

Dated: December 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 of GRO-B
GRO-B. I was born on the GRO-B 1963. I am married and I have no children. I gave up on my career in GRO-B in order to care for my late husband. I currently work part-time as a housekeeper.
2. I write this statement in relation to my late husband, GRO-B: H date of birth GRO-B 1951. He was infected with the Hepatitis B (HBV), Human Immunodeficiency Virus (HIV), and Hepatitis C (HCV) as a result of receiving contaminated blood products. H passed away on the GRO-B 1990, aged only 39, due to illnesses associated with the above infections.
3. This statement has been prepared without the benefit of access to my late husband's 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.

Section 2. How Affected

4. I cannot recall the details or dates of [H]'s Haemophilia diagnosis. For reference his older brother had Haemophilia and sadly died of internal bleeding aged [GRO-B]. If [H] was not diagnosed as a baby then he was certainly diagnosed in his infancy.
5. I believe that as a child [H] attended the [GRO-B] and possibly [GRO-B]. In his late teens when he moved to West Yorkshire he was registered and under the care of St James' University Hospital, Leeds (SJUH).
6. The earliest record of treatment that [H] received according to the National Haemophilia Database (NHD) (copy exhibited at 'WITN1470002') was Cryoprecipitate in 1969. This would make [H] [GRO-B] years of age.
7. I met [H] in 1980 (aged [GRO-B]) when we both worked for the [GRO-B]. Shortly after our first meeting he was off work for a period of 6-8 weeks. I later learned that his illness was in relation to HBV. I exhibit at 'WITN1470003' a copy of a letter, dated 17 June 1980 from Dr D.L Barnard to Dr [GRO-B] which confirm that 'he knows that he has knowledge of Australia Antigen positive hepatitis and that this is most likely the result of treatment with FVIII...'.
[GRO-B]
8. It was love at first sight. He always told everyone that he knew we would marry.
9. We started dating in [GRO-B] and within 6 months we had moved in together. We couldn't afford our own place so we lived with his mum and dad.
10. When we met I had never even heard of Haemophilia. We would both attend his clinic reviews, approximately every 6 to 12 months. He would also collect his home treatment which was Factor VIII (FVIII). I refer to exhibit 'WITN1470004' which is an extract from [H]'s NHD records. This list states that his last use of cryoprecipitate was in early 1970s and home treatment with Factor VIII started in 1977.

11. The Consultant Haematologist at that time was Dr L.M. Swinburne at SJUH, Haemophilia Unit, Leeds.
12. Along with Dr Swinburne in the early 1980s, Dr D.L. Barnard was also in attendance at the Haemophilia Clinic. Dr B.A. McVerry then took over the clinic from the mid 1980s.
13. Home treatment was administered for a variety of joint bleeds but mainly for his knees. His right knee joint became very problematic over the years eventually becoming osteoarthritic.
14. On the very rare occasion [H] attended the clinic by himself and at one such appointment he was told by Dr McVerry that he was HIV positive. (There were no noticeable symptoms which [H] had been suffering from at that time when he was told). He decided to attend by himself with the intention of asking Dr McVerry about HIV/AIDS because of what being said in the media and therefore he was shocked to learn that he had been tested for it.
15. [H] informed me of this news later on the same day. The hospital did not inform him of any precautions to be taken and no information to help understand or manage the infection was given.
16. I substantiate this because in the mid/late 1980s we asked Dr McVerry about starting a family. His advice was he could see no reason why not.
17. Fortunately for me, my own personal circumstances restricted me from taking the contraceptive pill so we took other precautions which undoubtedly saved me from being infected.
18. After much soul searching we decided against starting a family.
19. I'm certain that it was in October 1984 when [H] was told of his HIV diagnosis. I remember it being [GRO-B] after we were married [GRO-B] [GRO-B]. Please note that in the NHD records, an extract which I refer to as exhibit 'WITN1470005' dates the first positive test as being 15 January 1985, which I believe is incorrect.

20. Please also note that there is NO mention of any visit/appointment to discuss [H]'s HIV status in his medical records. In fact, there is no mention or reference of having a HIV discussion in his medical records for the period of 1984 to 1985. The first reference to a possible discussion about the positive HIV result is in a doctor's hand written clinic notes dated 1988, a copy which I exhibit at 'WITN1470006'.

21. In the medical records there are three HIV test results, dated 05.11.1986, 20.05.1987 and 09.05.1988 all which are exhibited at 'WITN1470007'. However, I believe there were previous HIV tests. I exhibit at 'WITN1470008' a Medico-Legal Report prepared for the litigation of 1990/1991, which clearly states that *"missing are the original HIV test reports and all reference in the notes for some time after diagnosis"*.

22. At the time we were not made aware of any difference in the FVIII products that [H] was given. We were of the understanding that all FVIII products available were without question safe and we were never advised or made aware of any associated risks with any of the products that he used.

23. There was never any discussion about available treatments. No options were ever given and at the time the doctor's word was the 'Law'.

24. [H] was a very loving, intelligent and protective husband who had a passion for motorbikes and also liked his cars. He was part of the biker scene in [GRO-B] Yorkshire and having gained his Instructor's Qualifications he would teach at the weekend.

Section 3. Other Infections

25. I suspect that during the 1990s [H] was exposed to vCJD and possibly other viruses.

Section 4. Consent

26. Blood was regularly taken on each visit to the clinic. We understood that blood samples were taken for the purposes of routine testing for Haemophilia clotting levels only.
27. [H] was never informed or consented to any testing for HIV, Hepatitis nor any other viruses. I therefore believe that he was tested without his knowledge and without his consent.

Research

28. Research is all very well but only with the consent of the individual concerned. I do not believe that [H] consented to any research to be carried out.
29. I refer to exhibit 'WITN1470009' (which includes 8 pages) which refer to a 'test dose' in [H]'s medical records dated 25 April 1985. There are references to various FVIII studies in the pathology lab reports dated 24 October 1986, 21 May 1987, 8 December 1987 and 25 April 1988. There is also reference to a HIV Test Report dated 9 May 1988 intended for research purposes only.
30. I also highlight "AIDS Surveillance: Clinical Report Form" dated 23 January 1989 which I feel very suspicious of due to its title and hand written notes. This document is exhibited at 'WITN1470010'.
31. I refer to medical record (hand written) dated 7 November 1983 in which it states that there is a medical reaction to a particular Factor VIII batch that [H] received. I therefore believe that they were testing different batches of FVIII for the purposes of research. A copy of this medical note is exhibited at 'WITN1470011'.
32. I refer to another suspicious letter, which was to [H] dated 17 April 1985, exhibited at 'WITN1470012'. Why is [H] being singled out for treatment? The treatment being offered was Factor VII.

Section 5. Impact

33. The first we heard about HIV/AIDS was through the TV news and newspapers in or about the mid 1980s. It would be mentioned in casual conversations with family and friends which we dismissed at first believing it was just a rumour. There was also chit-chat in the clinic waiting room with other Haemophilia patients but no one had told us that we should be concerned or that there was anything to worry about.
34. Eventually it was the TV adverts that contributed to the fear and uncertainty. The Government's public health AIDS campaign was at full throttle; warning of a plague of biblical proportions with no known cure transmitted by contact with blood or unprotected sex. The very notion somebody might have come into contact with someone with AIDS would immediately ostracize them.
35. The absolute horror of being told, along with having to keep quiet, was difficult. We didn't tell anyone of [H]'s HIV status for 5 years, not even his mum or dad. [H] felt the need to protect them; they were in their seventies and had their own health issues. It was only in the last 12 months of his life, when there was definitely no mistake of his condition, that we told them.
36. We lived a lie for 5 years, lying to friends and family. The weight of the secret was a strain in its own right and unfortunately put pressure on our own relationship.
37. We tried to draw away the suspicion but in the end it was easier to isolate ourselves rather than keep making excuses. Our friends and associates fell away as no doubt they had their own suspicions. Our true friends remained by our side though [H] still kept them at a distance.
38. It is difficult to capture that moment in time; the stigma associated with HIV/AIDS and the resulting overwhelming social isolation.
39. On the eventual realisation of the probable pending outcome, we were totally devastated. We couldn't bare the thought of being apart so we made a joint suicide pledge.

40. Even though I loved him, cared and nursed him; towards the end the only way I could cope was to be in denial. Mentally and emotionally he was slowly being destroyed and eventually he became a shadow of his former self.
41. [H] spent 20 years working for the local Government and was studying for his [GRO-B] qualifications but never had the opportunity to complete them.
42. Unfortunately [H] needed time off work because of frequent bleeds in his knee. Over time with this acquired infection this would become more frequent and in the end he retired on health grounds in September 1990 having already been off work for 12 months.
43. Fortunately for [H] and myself in the last 18 months of his life our employer was very accommodating. Previous to that point, frequent and lengthy periods off work due to ill-health were frowned upon.
44. In 1976 we suspected an infection as a result of [H] receiving contaminated blood products. In 1983, he tested positive for HBV and we believe that he was infected with HCV in 1988 because from 1989 onwards he had abnormal liver function tests which meant that most likely than not he developed cirrhosis.
45. The other medical conditions arising from HIV, HBV and HCV were as follows:
- a. Pneumothorax (recurrent problem),
 - b. Pneumonia,
 - c. Inflammatory skin conditions,
 - d. Enlarged spleen,
 - e. Inflammation of the kidneys,
 - f. High temperatures/shakes/fevers/drenching night sweats,
 - g. Depression and anxiety,
 - h. Insomnia,
 - i. Hallucinations,
 - j. Rigors associated with weight loss and loss of appetite,
 - k. Mouth ulcers and oral thrush,

- l. Bed sores,
- m. Short temper and
- n. Tired and generally unwell

46. In mid to late 1987 we noticed the first health issues which [H] suffered; pruritus (itchy skin). I exhibit a letter dated 10 February 1988 at 'WITN1470013' which confirms this.

47. In 1988 [H] suffered from more significant health issues such as inflammatory skin conditions, chronic pruritus and HIV showed itself in numerous symptoms. I exhibit at 'WITN1470014' a letter dated 20 June 1988 from Dr McVerry confirming that he would like to start [H] on a course of Zidovudine. He asks whether Dr Cunliffe has any objections to treating the pruritus as a HIV related phenomenon. From summer 1988, [H] attended the clinic every 2 weeks.

48. In 1989 another recurrent problem that [H] suffered from was pneumocystis pneumonia which is confirmed in a letter dated 6 February 1989. A copy of the above letter is exhibited at 'WITN1470015'. It was at this time that I believe he was also diagnosed with HCV.

49. In 1990 [H] suffered from more symptoms associated with HIV and HCV which showed themselves responsible for numerous conditions such as: pneumothorax, enlarged spleen, kidney parenchymal disease and inflammation of both kidneys which were shown by a CT scan dated 13 February 1990. Both the above letters are exhibited at 'WITN1470016'.

50. I have used [H]'s medical notes currently available to compile a list of the treatments which he was taking. These are as follows:

- o. AZT (Zidovudine) which was antiretroviral medication which commenced around June or July 1988. He stopped taking this medication as he was unable to tolerate it.
- p. Pyrimethamine,
- q. Gamimune intravenous infusion,
- r. Sandoglobulin intravenous infusion,

- s. Sandoz intravenous infusion,
- t. Beta propiolactone,
- u. Septrin,
- v. Venflon chest drain,
- w. Dapsone which was then replaced with Fansidar,
- x. Pentamidine nebolised prophylaxis,
- y. Immunoglobulin intravenous infusion,
- z. Nitrazepan,
- aa. Dermovate cream, synalar cream, triludan, haelan cream, propadern ointment, atarax, alpha keri, ultra violet light all used to treat his skin condition.

51. I had a breakdown 12 months after my husband passed away and I was off work for 12 months. By 1995 I had finished work and I have been unable to hold down a full-time job since then. I gave up on my studies and any prospects of a career in surveying.

52. [H] s parents were naturally very protective, particularly having lost their eldest son. They were a very tight knit family, a closeness that I had never witnessed before.

Section 6. Treatment/Care/Support

53. [H] accepted all treatments that were made available to him. We trusted that all necessary procedures and treatments for his care were being given. The progression of his illness was quite swift and within 3 years of noticing initial health issues he was dead! This is evidence of more rapid progression in people who were co-infected.

54. I do not recall [H] being offered or having any counselling or psychological support as a result of receiving contaminated blood products.

55. I organised and I paid for my own counselling sessions after he passed away.

56. The Haemophilia Clinic had its own in-house social worker. At the time we were registered with the MacFarlane Trust and administration was dealt with via our social worker.

57. We received payments for certain provisions and appliances such as a sun lamp for [H]'s skin conditions and a new clothes dryer due to the increased laundry due to his night sweats.

Section 7. Financial Assistance

58. In 1988/89, [H] received a £20,000 ex gratia payment which was initiated via his social worker.

59. During the 1991 litigation, [H] received £32,000 ex gratia payment posthumously as he was a married man with no children. He was in hospital when the proposed payments were announced on the news. He was devastated by the derisory figures. On hearing that statement, [H] gave up and sadly passed away before he was able to receive the cheque. I signed the waiver (a gagging order) on his behalf.

60. In August 2011, I received a Stage One lump sum payment of £20,000 from the Skipton Fund. I applied in March 2011 and was initially refused. It was only on appeal and with the intervention of the Haemophilia Society that I received this payment.

61. In August 2013, I received a Stage Two lump sum payment of £50,000 from the Skipton Fund. I applied in September 2011 which was refused and then turned down on appeal in February 2012. In August 2013 the decision was overturned due to an intervention from the Haemophilia Society. Their 2013 summer magazine to which I refer as exhibit 'WITN1470017' featured a case study by [GRO-A]

62. In March 2017, I received a widow's bereavement payment in the sum of £10,000.

63. Don't let anybody say that I, or we, have been compensated!

64. The ex gratia payments received come no way near covering financial losses and anticipated earnings. In 1989, [H] was off work for 12 months due to health issues, resulting in 6 months half-pay. As his condition got progressively worse it also became necessary to sacrifice my own career and studies.
65. In 1990 [H] passed away aged only [GRO-B]. It was a horrific and untimely death. I was left with a £45,000 mortgage. An endowment and life insurance was impossible to obtain. I applied and was denied widow's benefit because I was too young to qualify being aged [GRO-B].
66. In 1991/92, I suffered from a debilitation nervous breakdown 12 months after [H]'s death from which I have never really recovered. I subsequently lost my career and earnings as a result.
67. In [GRO-B] [H]'s superannuation local Government Pension was stopped when I re-married.
68. I am not in receipt of any annual payments from any of the Charitable Trusts; having previously applied to the MacFarlane Trust I was informed that any payments would be means-tested. I could offer and provide them details about my income but it is disgraceful that my second husband's pension should be taken into account.
69. There are no provisions for widows who are currently unable to access "ongoing payment schemes".
70. Given the scale and wounding consequence of the Contaminated Blood disaster we are deeply aggrieved that help for survivors of Contaminated Blood and their nearest and dearest should be based upon household income; even more so when one realises how the Government abandoned the infected and threw all the affected into the arms of charitable organisations.

71. I am infuriated at hearing about millions, schemes and funding. Russian roulette has been played with people's lives and along with many others through no fault of our own we have been put in a significantly difficult financial position (no endowment mortgage or life insurance etc).

72. Infections in Scotland took place under the same Westminster Government as those in England, Wales and Northern Ireland. Scottish reforms ensure that bereaved continue to receive 70% of their deceased infected partners annual payments. All the bereaved should be treated equally; WE HAVE ALL LOST.

73. In summary; I have been unable to receive life insurance, mortgage endowment, we lost [H]'s earnings and I lost my career and prospects of studying. The loss of my personal pension provision and ability to recover the lost pensionable working years. The loss of [H]'s superannuation pension, crudely estimated at £100,000.

Section 8. Other Issues

74. All those infected and affected today realise you have a professional role to perform within this process and you are respected for it. However, most (if not all) have families too. If someone you love, to whom you're returning home to, were infected; what would you fight for?

75. This entire matter revolves around life and death. Often it is impossible to control chronic ill-health beyond a certain point but surely we should remain mindful of "*first, do no harm*".

76. The emotional and financial cost is considerable and fuelled by an inherent mistrust of the Government.

77. In addition I would like widows who received pensions granted upon the death of a partner due to Contaminated Blood and who remarried to have their pensions reinstated and backdated. I have been lobbying for years for the reinstatement of my widow's pension which was suspended when I remarried.

78. I received a widow's pension from the West Yorkshire Fund approximately 20 years of pension contributions having been paid. When I remarried in GRO-B it was immediately stopped because widows/widowers who remarried had to give up their pension, this could however be reinstated if ones marital status changed; i.e. divorce or death.
79. In April 1988 the local Government pension remarriage policy was swept away under LGPS Regulations 1997; so from this date ALL widows and widowers irrespective of marital status have received lifetime pensions. It was not retrospective.
80. I challenged the changes to the LGPS Regulation 1997 as unfair when they were announced because they completely reversed the previous rules, and had the NHS not fatally infected my late husband the changes would have applied to his and my widow's pension. It is simply a question of timing; what happened to equality and fairness?
81. Even those widowed as a direct consequence of state incompetence and abject blunder were not exempted. I have been told by many Departments, squabbling over 'turf', it is not possible to make exceptions to this rule.
82. Government Departments have repeated many times; the LGPS Regulations 1997 are definitive, unequivocal and not open to challenge.
83. How can those responsible for H's infection and untimely death ignore 20 years of a hardworking man's Pension Contributions. I'm not asking for charity but the instatement of widow's benefit already bought and paid for.
84. I find it difficult to believe that pension contributions can be wiped out at the stroke with no compensation or consideration for individual circumstances, but the pension could be reinstated at the discretion of the relevant council when such a remarriage or period of cohabitation ended. Why should my pension arrangements necessitate a divorce?
85. Where have my late husband's pension contributions gone after my widow's pension was suspended?

86. If the pension can be reinstated if I cease to be married, it must still exist and must therefore remain invested somewhere. So, where have my husband's contributions gone?
87. Since the Government guarantees public sector pension funds it is within their gift to reinstate my pension and back date payments to when they were originally taken away, righting a wrong.
88. Had my late husband's pension contributions been paid into a private pension scheme I would be in receipt of personal lifetime pension; but in 1970s and 1980s the local Government employees were compelled to join their LGPS and it was against the law to have an occupational pension and an additional private pension simultaneously.
89. Maladministration, complacency and poor practice were directly responsible for killing my husband. No amount of money will bring loved ones back but denying a decent settlement for all is a further insult.
90. I do appreciate that there are so many permutations of people's needs. Treatment for NHS derived infections should be a priority and not form part of any support scheme.
91. I would also like to give my heartfelt thanks to "Tainted Blood" and all those associated with it. Without their help and dogged determination we would not be here today.

Anonymity, disclosure and redaction

92. 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.
93. I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-B

Dated

09/12/19