

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0356001

Exhibits: WITN03560002

Dated: 16 January 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth and address are known to the Inquiry. I worked as GRO-B GRO-B the City of London Police until 1992. I have been retired since 1992 due to ill health. I have lived at my current address since August 2018. I live here with my wife L and we have known each other since 1984. We have a daughter, who lives nearby.
2. I am a Haemophiliac, diagnosed with Haemophilia A moderate to severe, with less than 0.03 u/ml Factor 8, and I have suffered with this my whole life. I intend to speak about my contraction of Hepatitis C genotype 1a

following administration of infected blood products. In particular, I wish to cover the nature of my illness, how this illness has affected me, the treatment I received and the impact all of this has had upon myself and my family.

3. I am a member of the Haemophilia Society. I confirm that I am not legally represented and that I am happy for the Inquiry team to take my statement.

Section 2. How Infected

4. I suffer from Haemophilia A (HA), which is a congenital bleeding disorder. From the age of ten I was under the care of Dr, now Professor, Brian Colvin at The London Hospital, Whitechapel. I moved to Kings College Hospital London, in 1998 and in March 2007 I was moved to Guy's and St Thomas' Centre for Haemostasis and Thrombosis. I am currently under The Glasgow Royal Infirmary.
5. The first person I remember who prescribed blood products to me was Professor Brian Colvin. He was, by nature a scientist and while under his care we were required to create and send him Blood Logs of every bleed and how much product we took. We were very confident he knew what he was talking about.
6. The blood logs in my possession indicate that I rarely went for treatment, during some years I only had, roughly one treatment of Factor VIII. The rarity of my visits was due to me only going to hospital when the bleed was so severe, I had no choice, because of the sheer distance I had to travel to get treatment. The hospital made entries in the blood logs when they administered the treatment for those bleeds. This indicates that these institutes were keeping records at the time.
7. With reference to Hospital Blood Logs, I believe I began receiving Factor VIII Concentrate in 1978, although it is possible my treatment began

earlier than that date. The Factor VIII product name was NHS Elstree Factor VIII, followed by Proliferate.

8. From 1992, when I was able to treat myself with Factor VIII at home, I created tables in which I recorded my treatments. In the table dated June 1992 I noted down the Factor VIII details as Profilate SD/O (batch no: AR1247A).
9. I have been asked if I have tattoos and/or piercings, which I do not. I have also had very few partners with whom I have had sexual relations and I have never taken drugs intravenously.
10. I have received blood products from a very early age and during that time period, neither I nor my parents were informed of the risk of potential infection while using Factor VIII in a hospital or at home. At the time we considered Factor VIII to be a miracle.
11. As a result of my blood logs I believe that I have repeatedly been infected with Hepatitis B and C through repeated exposure to infected blood products.
12. I had an appointment with Professor Colvin in 1984 when I was shocked to hear of the risk of potential infection and so my blood was taken for testing. Several weeks later I was given the results, which confirmed that I was infected with Hepatitis B and C. At neither appointment did Professor Colvin sit me down and explain the consequences or the impact on my life that Hepatitis C would have. I was completely ignorant of the significance of the situation, I was young and unconcerned and felt fine. He should have made the significance clear to me.
13. Potential treatments were discussed, however the side effects were so severe and the success rate so low, that I decided to wait for

improvements in medication. It is a great shame that it took another thirty years for that option to materialise.

14. I was not given adequate information to help me understand and manage the infection. I should have been told to be aware of alcohol consumption. I did not understand why I could not drink as much as my friends and I did not know what damage was being done to my liver.
15. I was also not informed of the sexual risk to my partner L.
16. If I had known what to look out for, I may have been able to monitor myself. The symptoms take so long to manifest and are difficult to disentangle from my everyday life, such as headaches and tiredness. I appreciate that they were not certain what Hepatitis C was, but I believe they knew the effects of liver disease and so should have known enough to have warned me.
17. My results were communicated clearly to me, by Professor Colvin in a face to face meeting. It would have been nice to have been told my results by a doctor with a better bedside manner, however this is just the way Professor Colvin was.
18. I was not told anything regarding the risk of others being infected. L was not told to have a test to see whether she was infected with Hep C or HIV and was told that Hepatitis C was not transferred by sexual relations. She made her own decision to be tested.
19. Much later on, at Kings College Hospital, I was told by Dr Ayra about the need to separate towels and toothbrushes and to use condoms to control the risk of infection.

Section 3. Other Infections

20. I am unsure whether I have received any infections other than Hepatitis B and C as a result of infected blood products. I did receive a letter while I was at St Thomas', stating that I was at risk of contracting vCJD. This letter included no recommendations regarding testing for the condition or potential treatment of it, were I to be diagnosed as infected. My immediate thought was "you have to be taking the piss", followed by incredulity and laughter at the blasé attitude displayed by the letter. To this day I have received no follow up communication or support regarding this risk.
21. Furthermore, I have no doubt that, due to my weakened state and immune system, my body has suffered from numerous other illnesses during this period, which were either undiagnosed or remain unknown.

Section 4. Consent

22. Professor Colvin published research in 1986, *A prospective study of cryoprecipitate administration: absence of evidence of virus infection*, which may have included me. The research references a haemophilia patient who "was treated for a severe knee haemarthrosis". This may be me, because I suffered a severe knee haemarthrosis when I fell from a sledge and spent a long period of time recovering under his care, at The London Hospital, Whitechapel.
23. He has carried out a large amount of blood research in the relevant fields and, because I was his patient for such a long period of time, it seems highly possible that my blood was involved in at least some of his research.
24. Every time I had an appointment with Professor Colvin, he took routine blood samples and I do not know what was done with that blood.

25. If I had been asked to give my consent, for my blood to have been used for research purposes or for anything beyond my on-going care, I would have been reluctant to give my consent.
26. I have never given my consent and was never asked if I gave consent for research or testing of my blood.
27. However, Professor Colvin, did treat me totally fine and I believed the treatment he gave me at that time was the best.

Section 5. Impact

28. Living with the Hepatitis C virus for over forty years has had a devastating effect on my health and wellbeing. When I try to describe its effects to others, I liken it to having a hangover. In the same way drinking too much alcohol can overwhelm the liver and flood your brain with toxins, so with a cirrhotic liver, your system is drowning in unprocessed toxins. Only it's much worse, because it happens to you each and every day, week after week, year after year.
29. Some days you feel like you have been so badly poisoned you can barely function as a human being. You cannot move or think and getting out of bed is impossible. The lack of energy is so profound you are unable to move a muscle. Noise and bright light are extremely painful to endure.
30. The impaired brain function means most days you are unable to concentrate or make decisions. My short and long term memory is poor and I would frequently find myself in a room not knowing why I was there and what I intended to do.
31. It was impossible to judge how severely I would be effected from day to day. This unpredictability of symptoms is another aspect of the illness that makes life so hard to manage and bear. I had to constantly judge when to rest and when to be active to ensure I stayed as well as possible. If I

overstretched myself I would snap like a piece of elastic and be recovering in bed for the next three days. This makes any form of planning very difficult and I often had to make a choice between doing the simplest of activities with my family.

32. Fatigue haunts you daily. Knowing you need to remain active physically and socially to prevent atrophy and depression becomes a further burden because it all requires energy. Any activity has to be balanced with rest or I can soon become overwhelmed leading to disorientation and the inability to even speak. My self-confidence and ability to cope with the outside world dropped dramatically.
33. The days with bad fatigue prevent any social interaction. My mental and physical state was so poor that I could not communicate with anyone. If forced to do so I would become very distressed. On days when I was simply 'woolly' headed communication is difficult and I often misinterpreted what others say and I mumble. This causes anxiety before meeting with people, even those you know, because you do not want to make a fool of yourself. You become tense and self-conscious in such situations and therefore try to avoid them. It is the fear of not being able to cope. Even on 'good' days the fear remains, because your condition can change so rapidly.
34. During months of depression I went nowhere. Slowly I began to make attempts to socialise, because it is so important in order to feel alive, but be there is no doubt it has been a real struggle.
35. For years I felt I haunted this world like a ghost.
36. As a result of living with Hepatitis C I have also suffered from cirrhosis of the liver and brain impairment, causing short and long-term memory loss.
37. I have received three sets of treatment for my Hepatitis C.

38. The First treatment began at 22:30hrs on 14 September 2008 and was a course of Interferon and Ribavirin. I believe I was required to inject once a week. The second treatment, using Interferon and Boceprevir, took place in 2011. Both of these courses of treatment ended early because I failed the 1 log drop in my Hepatitis C viral load and therefore the treatment was known to be unlikely to be successful. My third treatment took place in 2015 and involved a course of Harvoni, which lasted for 3 months I think. This successfully treated my Hepatitis C.
39. I had some difficulties in accessing my third treatment. Harvoni had been approved for use but NICE were reluctant to roll it out to the Trusts. A few days before my treatment was due to start I called to check it was going ahead and I was told it had been cancelled by NICE due to the General Election. The hospital also lumped drug addicts and haemophiliacs together, and were worried that we would try and sell the Harvoni rather than use it. I was forced to make a lot of phone calls and put people in contact with each myself to try and expedite progress and decision-making. My haemophilia nurse knew less about the roll out process of Harvoni at this point in time than I did. NICE had begun new distribution methods, involving new distribution hubs. I spoke to a haemophilia nurse in the South London hub, who agreed I could have the course of Harvoni, however St Thomas' Hospital would not pay for the treatment. Eventually my haemophilia nurse persuaded the Hospital to allow me to have the course after huge amounts of effort on my part.
40. The side effects of the first and second treatments on me were severe. I had constant flu-like symptoms, including aching cold and nausea, chronic itching and hair loss. It felt as if it was leeching every vitamin and mineral out of my body.
41. The second treatment's side-effects felt far worse than the first's, maybe because I was now aware of how horrendous the side effects of interferon

were from my first treatment. I played mind games with myself during treatment, trying to frame it as a positive solution to my problems. However the mental strain was enormous on both myself and my relationship. L was very trepidatious regarding the second treatment and came close to vetoing it completely, because she found me almost impossible to live with during the first treatment.

42. During my third treatment the side effects were much more benign.
43. During my periods of treatment I maintained an online blog, which helped to explain to my family and friends how I was doing. Their messages of support helped to keep me going through the darkest times. I have supplied a copy to the Inquiry, this is exhibited as **WITN03560002**.
44. My infected status has not had an enormous impact on my medical treatment because, as a Haemophiliac, I had already had a lot of specialist care, so it wasn't all that different when I had Hepatitis C as well. Before having any operations I needed to disclose that I had Hepatitis C. Further, before an endoscopy operation at King's College Hospital I was asked whether I had vCJD, because they would have to clean instruments more thoroughly. I have never felt any of the medical professionals were unpleasant, they only took extra precautions because they had to.
45. The impact of being infected with Hepatitis C on my family and private life was dramatic. It put a strain on our love life because I had no energy and often simply did not want to. It had an enormous effect on L and she believes the onset of her early menopause and thyroid problems may have also been caused by the stress of supporting me. It has definitely drained her emotionally and physically, as she was required to be the main breadwinner, problem solver and organiser. The effect on my daughter was also strong, she's never known me as a healthy person; I've always been the person who is cared for. She has also had the constant worry that her father could die at any minute. This suffering has made us very close and strong as a family unit.

46. We wanted a second child, but L's very early menopause made that very difficult. Also I was not sure whether we could cope with having a second child, as I felt we were too vulnerable to do so. L would have loved to have a second child and we did try for one.
47. It is very difficult to go on Holiday and if we do, we usually have to keep it simple and close, such as France. We also used to go camping before that became too onerous for me. The other typical holiday problems are that when you book something you don't know if you can ever do it, due to the unpredictable symptoms and insurance cover is very difficult to obtain. We definitely stayed closer to home than we would have done if I had just had haemophilia.
48. It is very difficult for me, knowing the impact my condition and treatment has had on those around me. I can cope if it is just me. But when I see what it does to those around me, its very hard. I hate that it has had such an effect on L and my daughter. At times I have thought it would be better if I was on my own to suffer alone, and let them get on with lives. I wouldn't go as far as saying I was suicidal but I just didn't care if I died. I remember walking across a busy road with my eyes closed, not caring if I was hit. I was totally sick of the suffering that was being inflicted on those around me. THIS IS A BIG, IMPOSSIBLE THING TO MANAGE.
49. The impact of having Hepatitis C on my social life was that it has made mixing with other people very hard to this day, even though I have cleared the virus. This is because my memory is poor and I can suddenly lose the flow of a conversation in the middle of it. This prevents me from rebuilding my self-confidence. By nature I am an introvert, but I did enjoy company and I was pretty sociable before I contracted Hepatitis C. Even after this interview I shall be recovering from the tiredness for a few days.

50. When asked about the effect this had on my education, it is true to say I do not remember any real impact on my school days. However, if I had had more energy to do things when I was older, who knows what I would and could have achieved. I could have re-educated myself and tried a new career, but it was totally out of the question. I had no idea what I was going to be like on a day-to-day basis.
51. Getting a job now would be virtually impossible, people can't employ me like that. I feel like a burden on the state and I want to be able to give back. My role in life seems to be just "someone to be cared for", to date anyway. I had a good job in a good area and had to stop work due to the effects of my infection. This finally stopped my working career completely. I relied on L and so she didn't get to become the primary carer for our daughter, as she wished and she regrets that to this day. Even simple things, like making friends with other mothers in the playground, were denied to her. L didn't make the social connections and so she was more isolated; she would have preferred to work part-time and look after our daughter.
52. I have been on a pension since 1992 and L is currently unemployed. We are living on our savings and on the money that comes from the English Infected Blood support scheme (EIBSS) and the Employment and Support Allowance (ESA).
53. I have needed the assistance of a carer. I was assessed to need help by Lambeth social services; L and I couldn't cope. L would come back from work and the housework was not done, etc. I was allocated a personal carer 8 hours a week. I had to bend the rules a bit and get her to clean and tidy, rather than only helping me. It was a great help to us both, until funding was cut and she was withdrawn by Lambeth. They had decided L earned too much. We decided to pay for the carer's support ourselves. What they didn't take into account was that she was working full time, studying constantly, looking after me and looking after the house. At this time I was

psychologically much better when the carer could look after me. It also helped my relationship with L.

Section 6. Treatment/Care/Support

54. I have been asked to comment on any counselling/psychological support. I was not offered it and no-one asked after our welfare at the time of being told I was infected. As the Hepatitis C symptoms got worse they should have told me, 'stop being so stoic, we think you might need some help'. When I was ill with Hepatitis I was just surviving day to day and I was not aware of the psychological effect. I could not see the wood for the trees, and the Doctors should have been more proactive. It also would have saved a lot of aggro between L and I.

55. When I was on interferon help was made available, because I believe they knew it was psychologically challenging. I definitely think the support was inadequate and Doctors should have been aware of that inadequacy.

56. Group counselling would've been very useful if provided earlier. Later we had the choice to see a counsellor together or apart. We did see them together sometimes, but the majority of the time we chose to go on our own, because it allowed us to speak more freely.

57. My daughter has had good support through Lambeth. She suffers from anxiety and it is likely living with me and my condition has aggravated it. She has had counselling up until today, starting when she was 14-15 years old. She has been taking medication for the anxiety until roughly one and a half years ago.

Section 7. Financial Assistance

58. I can't remember when I was specifically told about the financial assistance available. However I am a member of the Haemophilia Society

and that was the primary portal that made me aware of funding and allowed me to apply for funding very early on in 1984-5 when I was diagnosed.

59. I had no problem getting on the various schemes.

60. I received a £20,000 lump sum payment from the Skipton Fund, during or just before 2011 I believe.

61. I have also received a further £50,000 lump sum from the Skipton Fund, once it was established my liver cirrhosis was sufficiently severe. I think I received this in two lump payments.

62. Between 22 November 2011 and March 2017 I was receiving approximately £1,100 a month from the Skipton fund. The EIBSS have continued these payments since then.

63. I also receive approximately £500 a year in Winters Fuel Allowance.

64. I also receive an Employment and Support Allowance.

65. The process of applying for assistance from Skipton involved filling in a form and having supporting evidence from my physicians and then I was paid. The forms were not hard to complete, but the problem I had was proving that I had a stage 2 cirrhotic liver and once I had a scan proving this, I got the second payment of £50,000.

66. The payments did take a while to arrive.

67. I made an ESA application in Feb 2017 and the interview assessment was in Sep 2018 and then I had to wait for 8 weeks before we got an answer. Interview required me to go to Glasgow to meet with an assessor. You do not know how ill you are until you do a questionnaire for disability

allowance; so many cold questions and it was so depressing. Questions included 'how many steps can you walk?' and 'can you use steps?'. The answers to these questions would change depending on the day in question. For example, if I have a bleed on a load bearing joint then I cannot use steps that day, but on other days, without a bleed, I would be fine to use the steps. IT WAS AN ABSOLUTE NIGHTMARE. I had to emphasise my worst days in order to get the most points at the end of the enormous application.

68. During the interview the assessors treated my application like it was not a medical issue and more of a tick box exercise; if you give the wrong answer, you have lost a point and therefore you may lose the funding. I definitely did not feel like the assessors were on my side and there to help me.

69. I found it extremely stressful and wouldn't want to go through it again, as I do not want to keep on being reminded how ill I am.

70. As a result I get ESA payments.

71. ESA sent me a letter, while I was away on holiday for four weeks, telling me I had to reapply for the funding I had. By the time I got home they had removed my funding. However, they realised they had made a mistake and the taking-off process had happened too quickly and so they reinstated my funding. The stress this caused, right after I had returned from my holiday, was extreme.

Section 8. Other Issues

72. I can confirm that I have had no involvement in any earlier litigation concerning the use of infected blood products, neither have I had any involvement in other inquiries, investigations or in campaigning in relation to such matters.

73. I require anonymity when my statement is disclosed or published for the purposes of the Inquiry.

74. I have been asked if I would like to put any questions to the Inquiry and I would, and these are as follows:

For Bart's Trust:

1. Who ordered the destruction of my records?
2. Why were they destroyed, contrary to Bart's Trust protocols?
3. Were all haemophiliac records destroyed or just mine?
4. What involvement did Professor Colvin have in any of these decisions?
5. Was I (my blood, etc) involved in any medical studies or scientific research whilst I was in hospital? If so, what studies or research?
6. What date did the hospital know I had contracted Hepatitis C?
7. What date did the hospital inform me I had contracted Hepatitis C?

For the Government:

8. Why was the threat of NA-NB Hepatitis not taken seriously when it was first discovered?
9. Who stopped David Owen's plans for a self-sufficient blood transfusion service? And;
10. What was the logic behind such a decision?

Statement of Truth

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

GRO-B

16 JAN 2019

Signed

GRO-B

Dated 15 January 2019