Witness Name: GRO-B

Statement No: WITN0254001

Exhibits: WITN0254002 – 009

Dated: 14 July 2021

INFECTED BLOOD INQUIRY

STATEMENT OF GRO-B

I, GRO-B, will say as follows:

Section 1: Introduction

1. My name is GRO-B. My date of birth is GRO-B and I currently live at GRO-B.

2. I am the second oldest of 4 siblings. I was GRO-B at 3 weeks old and was rushed to hospital as I continued to bleed out following this procedure. It was a year later that my haemophilia diagnosis was revealed following an incident where I fell and the bleeding would not stop. It was found that I was Factor VIII deficient. At the time I was considered to be in the severe category as my level was less than 1%.

Section 2: How infected

3. I was born in GRO-B and again, it was found that I was haemophiliac following a fall. My mother was tested and confirmed to be a carrier for the gene, despite there being no history of haemophilia in our family.

4. As a young boy, I remember being informed of my haemophilia by my mother. My school was also informed and they proved to be very supported. As were my peers in my community.

5. When I was around 15 years old my younger brother died, this seems to have triggered my anxiety as I developed OCD habits a short time after and I still suffer from it to this day.

6. Looking back, the next situation that stands out was when I was around 16 years old. This was when my mother told me that I was diagnosed with HIV. My parents had delayed telling me as I was found to be HIV positive in the 1980's, **WITN0254002**. I remember being so confused and shocked, but it was just another condition that I had to deal with. I sort of took it in my stride. At the time, I never made any connection with my younger brother GRO-B: B who had passed away or that he had died as a result of his HIV status. Upon realising this, I immediately felt that I was carrying a big burden which was weighed down by its own consequences. It was not until I was around 18 years old that I was able to join the dots.

7. I began reading more and more letters that would arrive and I slowly realised HIV was serious, until then I didn't think it was a limiting illness until one of my doctors, Dr Ian Williams commented that there may be issues with mortality and that my life span may only be guaranteed until the age of 30, **WITN0254003.**

8. This caused huge anxiety and depression which had a long lasting effect on my mental health.

9. As I grew up I was always more lethargic than my peers and this was a common factor through my life, seriously affecting my quality of life and this seemingly got worse after my interferon treatment.

10. With the benefit of reviewing my medical records, it is noted that I was diagnosed with non A non B hepatitis in 1989 **WITN0254004**. I cannot recall the date that I was informed of my Hepatitis C diagnosis, however I believe I was aware of it from 1997, **WITN0254005**.

11. I received triple therapy around the age of 15 and between the years 1994-1997 I received pegylated interferon until around 2002. This treatment was terrible. My quality of life was very poor during this period and it was one of my lowest points.

12. This treatment made me feel awful and depressed. On top of feeling very isolated and rejected by society as I was not able to build a family like my friends who were nearly all married already. This had a deeply crushing effect on my mood and self esteem and this was along with my ongoing fatigue.

13. I relied heavily on my parents and received a significant amount of support from them.

14. I attended Great Ormond Street Hospital until the age of 18/19 which I now appreciate was late seeing as I was being treated at a children's hospital but at the time I was not conscious of this.

15. Throughout my treatment, I always felt that I received better treatment from my Consultants which may have been because they felt that what had happened to me was completely out of my control or maybe they thought that I might not survive, and I was being pitied. I feel that the system has looked after me.

Section 3: Other Infections

16. I had Lipodystrophy, which I am aware features as a result of my HIV status, **WITN0254006.**

17. I continue to hide my facial features behind a beard. I still appear thin all over except for my stomach which is rounded and feels like there is a "*ball in it*". Lipodystrophy has reversed slightly but not much. I have suffered enormously with loss of appetite, and chronic fatigue. I have never been diagnosed with chronic fatigue syndrome however my energy levels have not improved. There continues to be a long-term impact on my day to day life.

18. At one point Dr Liesner at UCH mentioned to me that I ought to know that I was exposed to vCJD. This caused a great deal of anxiety as it was rarely discussed and

I should have been informed. Any such potential exposure creates enormous panic and uncertainty.

Section 4: Consent

19. During the course of my care, I believe that my parents nor I were ever informed about the risks associated with the treatment I received.

20. My mother has informed me that she nor my father were ever informed of any risks, or potential risk associated with the haemophilia treatment.

Section 5: Impact

21. GRO-B
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22. I found out the true impact of my HIV status when some friends were getting married and I began looking for a wife.

23. When I became 19, which is around the age when my friends started to get engaged, I discussed my situation with my mother and she advised me that because of the infectious nature of my disease I may not get married like my peers and build a family.

24. This news had a profound effect on me and I got very anxious and depressed however at around 22 years my doctor informed me that with a sustained viral load the risk of infection is low and marriage could be possible.

25. Due to the fact that my HIV status, my parents were of the view that marriage for me would be a remote possibility as my status had to be revealed to any marriage prospects. I became very anxious and depressed because of this, the thought that I may never marry nor have children was overwhelming. By that point I truly found out what my HIV status meant.

26. Within the community, I believe it was accepted that haemophilia was a manageable condition that could not be passed down. However, when it came to my HIV status, people ran scared. They realised that it was a very different set up when it came to family and it could carry serious health complications.

27. With my health concerns, it was a lot more difficult to establish a relationship in my own community. It prevented it. The condition had other connotations with it also– death, stigma, being ostracised. It was difficult to find any person who would welcome someone with my medical history into their family.

28. Up to the age of 19 I threw himself into my studies and became very educated. Admittedly, due to my love for studying, I could have become very successful in any chosen career but for the effects of my HIV and Hep C status and the treatment I received.

29. However, between the ages of 19 and 24 my ability to study and my passion for it diminished quite significantly, especially when I had the Hep C treatment.

30 GRO-B I had a very hard time getting families to accept me because of my haemophilia status but we did find on 2 occasions when I nearly got engaged but when we finally informed them of my HIV, I was rejected.

31. As you can imagine all of this had a very significant impact on my mood adding to my anxiety and causing me a lot of low times and this on top my fatigue.

32. I decided to travel to GRO-B to study and decided to attend sessions with a psychologist. At this stage in my life, the HIV had become undetectable.

33. When I finally got engaged at 24 years old I was really pleased GRO-B GRO-B

34. Eventually, I married albeit outside of my own community. My future mother and father in law's background was completely different to that of my own community. My future wife's family were made aware of my health status and I was accepted by them. I felt

that my future in law's accepted my status because their daughter would be seen to be "marrying up" and it would help her parents be accepted within my community.

35. Once I got married my anxiety had still not calmed down although my depression and OCD tendencies had improved somewhat.

36. Our families were already good friends and that is how the successful match came about. I have been married since and we have 9 children, ranging from 2.5 year old twins to my eldest who is 17.

37. Despite being very happy to marry, the stigma still lingered as I did not marry into the community. I stepped outside of "the norm" but the community would not have known the reason why. Notwithstanding this, when I walk around, I still feel that sometimes I am being treated differently by the community.

38. When I was around 24 years old, I was told that the prognosis of my status, at that stage was that it was a lifelong management condition.

39. I was told that it was impossible to infect my wife when my levels were so low. However, I was aware that Hepatitis C was not a manageable condition and could turn much more sinister and I was aware of that taking my life.

40. Interferon therapy brought on depression severely, I still suffer from depression and extreme anxiety. I attended a psychologist who informed me at one stage that my anxiety reverts back to the death of my brother, although I was not aware of this but through therapy I realised that this is true.

41. Because of the effects and impact of my treatments I was unable to take on a fulltime job, so we continue to struggle financially. Without the help of my parents and family we would not be able to cope.

42. I cannot accept employment even when I am available. I continue to study, undertake voluntary work when possible and provide lectures from time to time. My health differs from day to day, one day I am fine and the next my energy levels are so low I can do no work.

43. My ability to focus on my studies was never the same as before (from after the age of 19) and even once I got married it still did not bounce back completely as I hoped it would.

44. Even when I can focus I lose my energy very quickly so I need to rest a lot or eat something sweet to regain some of my strength. This has reduced my passion for life in general and for my studies in particular and sometimes leads to depression.

45. Some days I have some energy and other days I cannot do much other than take the children to school.

46. Due to my lack of energy, I was never in a position to fulfil my potential. Even though I would class myself as reliable, I would end up being unreliable in a working environment due to my health problems. This was a huge loss of opportunity and it greatly impacted on my self-confidence – it made me question my self-worth and self-respect. It drains a person.

47. By nature I am a high achiever although there are some goals that I cannot achieve and then I lose the passion for settling any further goals.

48. Upon reflection, I know had I avoided the virus I would have had a great career and would have been capable of providing for my family and been in a position to provide a much better quality of life for myself. We would be living better than we are now. As a family of 11, we are in dire financial straits but the help from our family does help from time to time.

49. For a very long time probably since around my early twenties, on average I am used to getting up in the morning very energetic but around 2 hours later I am really exhausted and I need to rest in the day a lot and find something to refocus my energy on so that i don't get down.

50. On a bad day I already feel exhausted in the morning and because of my fatigue etc. looking after my wife and family can become very tiring very quickly hence the need for a lot of paid help to assist my wife to do basic household chores.

51. My wife carries 90% of the burden of the household and family. She also does most of the physical work. For instance, when she was in hospital giving birth to our twins,

I had to look after the 7 remaining children and it really drained all of my energy, even though my mother helped in looking after them.

52. From time to time, the children would ask me questions as to why I have more free time, the questions became more searching with time. I would just tell them that I am a weaker person. With respect to my daily medication, they think it is haemophilia related.

53. My children are not aware of my condition. I do not think they are ready nor would they understand. I fear that it would impact on them negatively. Whilst I feel like I am living a lie, unfortunately I have no option but to get used to it. The fear of being discovered is a very stressful situation which is not easy, but again you get used to it.

54. Severe depression set in in addition to all of the above as a result of the Interferon treatment and I became very anxious. My anxiety caused issues, but I only ever took prescribed medication (Citalopram) at the onset of my depression which set in during the Pegylated Interferon treatment. The severe side effects of the treatment lessened once I finished the Interferon treatment and therefore I was able to stop taking medication.

Section 6: Treatment/Care/Support

55. My treatment history consisted mainly of Factor VIII concentrate. As a young boy, I experienced spontaneous bleeds usually into my muscles, which settled rather quickly when treated with Factor VIII concentrate.

56. I believe Factor VIII concentrate was the cause of my HIV infection.

57. I was transferred from Great Ormond Street Hospital to the Adult Haemophilia Service at UCLH in early 1998. I had less frequent bleeding episodes and so was on prophylaxis treatment for my haemophilia with recombinant Factor 8.

58. I remember that we had to go to three different clinics then, the third being the liver clinic in UCH. There was no effective treatment for HIV at the time. I was under the care of Ian Williams, Consultant and later on I attended the Royal Free.

59. With respect to my HIV infection, I cannot recall any major symptoms. I was treated with AZT from 1989 – 1995. When data became available suggesting that combination therapy was better than monotherapy, I commenced 3TC in addition to the AZT.

60. From review of my records, at that point my CD4 count had dropped however I continued to have no symptoms. I commenced triple therapy in 1997.

61. These treatments supressed my HIV infection to a point where it is undetectable, **WITN0254007.**

62. With respect to my Hepatitis C infection, while there was no evidence to suggest any progression of liver disease, all liver function tests that were carried out were monitored and returned abnormal. These results were kept under review as I did not want to commence treatment in light of emerging clinical trial results.

63. I started pegylated Interferon and ribavirin treatment in May 2002. I tolerated the treatment as best I could however, the treatment took its toll on me physically and mentally. Shortly after treatment started, my mental health began to decrease and I was prescribed antidepressants to manage the obsessional anxiety that I was experiencing as a side effect of the treatment. **WITN0254008.**

64. At my 28 week review, it was agreed that my treatment would stop due to non-response. **WITN0254009.**

Section 7: Financial Assistance

65. My family and I are on benefits. We also received from money from the MacFarlane Trust and the Skipton Fund, amounting to £30,000 and £20,000 respectively. We receive regular payments from the EIBSS however there are no funds left over for luxuries and what we receive covers our basis everyday household expenses.

66. I have recently been in receipt of a fixed payment in the sum of £100 per child. However, as I receive a rental rebate of £36,000 per year, I have been informed that I will lose this fixed payment as the child support payments are now means tested.

67. Currently, all I receive is a payment of £3756, which includes a payment for my Hepatitis C. As child support has been means tested, I lost £900 per month from my HIV benefit. This is very unfair, no consideration was given considering the money I receive is to support my whole family. I am deemed a high-income receiver due to the fact that I receive a substantial housing benefit, which falls under the umbrella of my "income". I do feel that if my family and I lived elsewhere eg. Gateshead we would be better off financially as the standard of living would be similar to that of living in London however my "income" would be below the means tested threshold due to less expensive housing costs, which in turn I would receive a lower housing benefit and therefore I would be entitled to receive the child support.

68. I appreciate that the aim and objective of the EIBSS is to support people and their families who have been infected with Hepatitis C and/HIV from contaminated blood/blood products. However, I fail to understand why the scheme suddenly changed in 2017 to incorporate means testing of its beneficiaries who were previously in receipt of the child support payments. While my HIV payment was upgraded, my child support payments were suspended. Even with the passage of time, I am still in shock by this, the upgraded benefit was given with one hand and the child support payment taken with the other. I feel that I have been penalised for where I live, for wanting to remain close to family who I rely on for support.

69. Whilst I am very grateful for the benefits that we do receive, I do feel that the scheme discriminates against people with big families in the Hep C/HIV community due to the fact that the child support scheme is now means tested. While I am aware that not all beneficiaries have large families or have families at all, I do feel like a lone voice.

70. I have now fallen into serious debt. It was suggested to me that I should declare myself bankrupt, but I was not willing to do so. I previously liaised with StepChange Debt Charity and they have set out a scheme with my debtors where I will pay £250 out of my benefits through their charity.

71. My wife does not work outside of the home as she carries the burden of running the house and taking care of our 9 children. My inability to help around the house means that she continues to the do the majority, if not all of the housework.

72. All of the issues combined with the financial situation makes everything else a lot more difficult to deal with and your mental health inevitably takes a blow.

Section 8: Other Issues

73. My brother B died when he was just 12 years old. His loss impacted greatly on me as we were only 3 years apart. My anxiety was through the roof when he died. It was only later on that I was able to put 2 and 2 together.

74. My outlook on life changed afterwards. His loss affected my view on life expectancy. As my level of knowledge evolved I had a much more real view on life as my brother had navigated that road previously.

75. I no longer had the cushion of ignorance being bliss.

76. My Hep C virus has now been negative since my last treatment in 2016. I received treatment from the Royal Free Hospital over a period of 12 weeks. This treatment can in no way be compared to that I received in the past, to the point where I was surprised how little I was affected following it.

77. Thankfully it was successful and I no longer have to attend that clinic and my liver has not been affected. I have not been told of any difficulties that might arise and subsequently have been fully discharged from the Hep C clinic.

78. In terms of my energy levels, I had hoped that they might have increased post treatment but unfortunately that was not the case.

79. So, in light of all the above I could never consider applying for any job as I could not commit to any work as my mood and energy is nowhere near what it needs to be to commit and this is despite me being considered by my peers as an intelligent and qualified person. The fatigue, anxiety and depression has also affected my memory and ability to analyse and retain information so I have now slipped behind my peers, even just in the academic level and I would now not be considered up to par with my qualifications.

80. I always try to occupy myself to make my life better. However it is difficult when I am faced with those quiet moments, I always avoid those moments as much as possible to escape those negative thoughts.

81. I would like to stress that money would never bring back what my family and I have lost at the hands of receiving contaminated blood. Being in a better financial situation as an infected person would improve the quality of our lives where we already find it difficult to deal with life and the worries that come with wanting to provide for your family. Ongoing financial support, private medical insurance, the reinstatement of child support payments as well as receiving compensation would greatly improves ones life and ones future.

Statement of Truth:

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

Dated the 14 day of July 2021

Signed: GRO-B

GRO-B