Witness Name: GRO-B
Statement No.: WITN0218001
Exhibits: **WITN0218002**
WITN0218003
WITN0218004
Dated: 7 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 1 March 2019.

I, GRO-B, will say as follows: -

Introduction

1. My name is GRO-B. My date of birth is GRO-B and my address is known to the Inquiry.

2. I am and have always remained single. I lived with my parents throughout their life. Following my mother's death from cancer in GRO-B 2007 I took the decision to quit my employment as a local government officer and served the requisite period of notice in order to spend quality time with my father until he too succumbed to cancer in GRO-B 2013. I have one older brother who lives close by and we are in regular contact.

3. I can confirm that I have chosen not to have a legal representative and that I am happy to provide the Inquiry team with a written statement.

4. In this statement, I intend to speak about my co-infection with HIV and Hepatitis C. In particular, how I was infected, how the illness affected me, the treatment I received and the impact it had on my life.

How Infected

5. I was infected with HIV and subsequently Hepatitis C through the use of contaminated blood products used to treat my haemophilia.

Background

6. I suffer from inherited severe Haemophilia A, diagnosed when aged about 2. I was told by my parents that two older cousins had been swinging me by my arms, and that after they left for home I was unable to move both arms. I seem to recall that the diagnosis had been made by a local doctor, whereafter I was referred to the Sheffield Children's Hospital in whose care I remained until my early teens when I became eligible for the specialist care of the Haemophilia Centre within the Royal Infirmary, Sheffield, South Yorkshire. My older brother does not have haemophilia.

7. During the early 1960s I was treated with fresh frozen plasma by transfusion, but the plasma contained so little Factor VIII clotting factor that copious quantities had to be used. In the late 1960s I was treated with cryoprecipitate, though I still spent many long hours attached to a drip device. During the 1970s freeze dried powdered concentrates of Factor VIII became available and these revolutionised treatment because these could be safely stored at home in a domestic refrigerator. Between the ages of 2 until the age of 15, I was treated as and when the need arose, but being a child I would imagine the treatment was provided to me on a regular basis. I cannot be specific and can only imagine my parents' anxiety during my childhood.

8. In 1976, shortly after my 15th birthday, I was offered "Home Treatment" by my Haemophilia Centre within the Royal Infirmary, Sheffield, South Yorkshire. I was shown how to inject myself intravenously so that I could treat any bleeding on demand at home, effectively minimising pain and discomfort, and travel time to and from hospital in most situations, save where urgent medical intervention was demonstrated.

9. My first batch of Home Treatment was issued to me on 18 July 1976 and first used on 29 September 1976.

10. I was required by my Haemophilia Centre (originally within the Royal Infirmary, Sheffield until its closure and demolition, and subsequently by its replacement, the Royal Hallamshire Hospital, also in Sheffield, in or about 1978) to document all bleeding episodes, quoting batch numbers, date of issue, date of use, the nature of the bleed, and time before return to normal activities.

11. In addition to keeping a paper record for the hospital's use, I kept a record for my own use and maintain this original notebook to this day. As a result, I have prepared a document with details of all the batch numbers contained therein **(WITN0218002)**.

12. From the abovementioned records, I have gleaned that I received products from Austria, Armour, Lister, Koate, Hemofil, Monoclate P, and later on Recombinant and Elocta.

13. Sadly, I cannot recall if my parents were provided with any information or advice about the risk of me being exposed to infection as a result of blood products, but I suspect that they were, either through the content of a national newspaper, a Haemophilia Society bulletin or by me personally after having attended one of my many regular Haemophilia Centre review clinics during the mid-1980s.

14. Certainly, at some time during one or more of these review clinics I recall that I was provided with information about the risks of blood products because I remember asking the doctor, who I believe to have been Dr Charles Hay, though in fairness to Dr Hay I cannot be one hundred per cent sure of the doctor's identity, in or about early 1985 to let me know at once if the results of the blood tests should give any cause for concern. That said, in order to enjoy and maintain a decent quality of life, I had little choice other than to continue with the treatment then supplied to the hospital and subsequently prescribed to me.

Diagnosis

15. Medical records obtained from my Haemophilia Centre within the Royal Hallamshire Hospital, Sheffield show that I tested HIV positive on 3 April 1985 and Hepatitis C positive on 12 October 1991.

16. As regards my HIV, I recall that when I attended my review clinic on 2 October 1985 I specifically asked if my blood tests taken previously on 3 April 1985 were still okay, only to be told the sickening news they had come back positive. A letter from Dr Charles Hay to Dr F Preston and Dr Greaves dated 3 October 1985 states that I did not appear to have been specifically counselled about my positivity, had to ask about the results myself, and was subsequently given a "wee chat" about it by Dr Hay **(WITN0218003)**. I vividly remember walking from the hospital back into Sheffield city centre to meet up with my parents and having to tell them of the situation I was now faced with. My parents were clearly shocked and disappointed and expressed their regret. Little more was said.

17. My medical records also note that on 22 January 1986 I was given counselling about my HTLVIII positivity by Dr M Greaves and Sister J Farnsworth, when I recall being told about the precautions I should be taking, such as not to share toothpaste, razor blades, not to donate blood, not to donate organs, to inform my dentist and anyone who needed to take blood, and being asked if I yet had a girlfriend, and the precautions I should take in that eventuality.

18. As regards my Hepatitis C positivity I cannot recall when I was first informed but am confident that I would have been told, although the first recorded entry specifically highlighting this condition appears to be that shown in my medical records on 12 August 1992.

Other Infections

19. As if these related conditions were not enough, I was subsequently notified that I am "at risk" for Public Health purposes of vCJD in a letter dated 23 December 2004 written by Dr Hampton, one of my Haemophilia Centre consultants **(WITN0218004)**. The effect of having this knowledge of being at risk of vCJD is just one more potential issue to contemplate and bear in mind.

Consent

20. I am completely satisfied that I have never been tested without my knowledge or consent and would go so far as to say that all discussions with my clinicians within the Haemophilia Centre review clinics have at all times been open and frank.

Impact

21. Initially, I was shocked and immensely disappointed at being told of my exposure first to HIV, and subsequently to Hepatitis C, through the use of contaminated blood products, prior to which they had been safely and successfully used over many years for treating my severe Haemophilia.

22. At the time of my HIV diagnosis in April 1985, I was just 23 years old and in the prime of my life. I questioned my life expectancy: how long did I have left? Would I see my next birthday, the milestone birthdays, 30, 40, 50? Would I celebrate my parents' anniversaries? Would I see my nephew and niece grow up, marry, see their own children? Would my parents outlive me? I questioned whether I should continue to save for my future, my retirement from work, or should I live in the moment and spend all my money in the time that I had left?

23. The mental effects of being infected with both HIV and HCV are that these conditions are always at the forefront of my mind and can never be dismissed as trivial or insignificant, but moreover lifechanging.

24. Due to the stigma of HIV, I did not know who to tell, how to tell it and when it was appropriate to do so.

25. Other than my parents (now deceased), only my Haemophilia Centre and my specialist Dental Hospital (built alongside my Centre) knew of my co-infection. It was in fact, only in very recent years that I felt it was time to confide in my local GP, bearing in mind I live in a small market town.

26. As stated at paragraph 16 above, my parents were clearly shocked and disappointed and expressed their regret at being told of my exposure first to HIV and subsequently to HCV and agreed no-one other than my hospital and dentist needed to know, save in the event of necessary blood tests when those involved would be forewarned of my status so all necessary precautions could be taken.

27. This resulted in many decades of secrecy, barefaced lies, and suffering in silence. Even to this day, my elder brother is wholly unaware of my co-infection, my treatment regime, and the side effects. All medical advice and recommendations given to me had to be carefully considered, researched, and balanced wholly alone, with subsequent decisions also taken wholly alone.

28. As soon as I was told of my HIV positivity, I resigned myself to a life of living alone, ending close friendships and probable relationships. I would not have a wife and children, no daughter-in-law and grandchildren for my parents, and no nephews or nieces to grow up alongside, play and interact with my brother's children.

29. The physical effects of being infected with both HIV and HCV are more fully set out in the following paragraphs.

30. When treating all bleeding episodes intravenously, and especially while experiencing external bleeding (such as cuts, grazes, nosebleeds, and blood in urine) I have to be extremely conscious, careful, and at all times vigilant regarding my personal hygiene and the prevention or containment of any drips, seepage, or splashes (almost to the point of obsessive behaviour) in order to protect others from coming into contact with my blood, preventing others from trying to help, but while still trying to remain discreet, composed, and in complete control of the situation.

31. Inevitably, with the passage of time, and due to a steadily declining CD4 count coupled with a rising viral load (both of which had been continually monitored by my Haemophilia Centre at regular 3 monthly clinics since 2 October 1985), I was strongly advised to start triple antiretroviral HIV medication consisting of Abacavir/Lamivudine and Efavirenz with effect from 1 April 2008, (April Fools' Day - except this was no prank!) such medication to be taken both morning and night thereafter, indefinitely.

32. I have to remember to take my HIV medication regularly and punctually at the same time each morning and evening so as to prevent such medication from losing its effect and the virus breaking through. The effect of this medication is to keep the virus suppressed and inhibit its ability to make more copies of itself. I was warned not to exceed the recommended daily dose. Should I forget to take it on time, I must take it as soon as I remember. I am warned never take a double dose to make up for a missed dose. Accordingly, I must keep a dosette box in order to monitor the exact amount and usage of my medication. I must remember to pack this dosette box whenever away from home and carry sufficient spare medication, too, should I encounter any delays.

33. I suffer from ongoing and recognised side effects of my HIV medication: difficulty getting to sleep, restlessness, diarrhoea every single morning (an urgent need causing embarrassing accidents). I am unable to leave home or plan or schedule any day out without first having been to toilet, effectively ruling out early morning walks and early morning travel in any shape or form (such as car and train journeys, coach trips and holiday flights). All told, this is a significant restriction on my day to day activities and routines and, in all probability, is the scenario I must expect and accept for the rest of my life.

34. By pure chance, through having left full time employment just one year prior to the commencement of HIV medication, my former colleagues never needed to question my daily toilet difficulties or speculate the probable underlying cause, something in which I take considerable comfort.

35. Shortly after my 50th birthday, on 9 June 2011, I commenced Hepatitis C treatment regime requiring self-administered weekly abdominal injections of Pegylated Interferon and Ribavirin, followed by weekly Haemophilia Centre check-ups (with constant adjustment of dosage), over a period of 48 successive weeks, ending 9 May 2012. Now, I am considered to be Hepatitis C PCR negative, but for how long?

36. Fortunately, I experienced no side effects of the HCV treatment at all, and much to the astonishment and surprise of my specialist doctors and nurses who in fairness had fully appraised me of the potential risks.

37. I have never faced any difficulties in accessing treatments for HIV or HCV. I am perfectly satisfied that HIV and HCV treatments have been readily offered and made available to me at all times. As far as I know, and have been told by my specialist doctors, no medical complications or conditions have resulted from the HCV infection. My infected status has not in any way impacted upon my treatment, medical or dental care for any other conditions.

38. However, I have to question if there are any other as yet unidentified viruses which have yet to surface. The long-term effects of the medication are unknown, and coupled with the knowledge that I have probably been exposed to vCJD, mean that I can never really be at peace with my situation, so giving me no long-term optimism.

39. I am completely satisfied that I have not at any time experienced educational, work-related, or financial effects (excluding the grant and scheme payments discussed below) through being infected with HIV and Hepatitis C.

Treatment/Care/Support

40. Similarly, I am completely satisfied that I have not at any time faced difficulties in obtaining treatment, care and support in consequence of being infected.

41. Counselling has probably been made available to me as a consequence of being infected but I have never considered this to be necessary, perhaps because of the close support and reassurance of my late parents and clinicians.

Financial Assistance

42. I believe I found out that financial assistance was available from both the Macfarlane Trust and the Skipton Fund, through being a lifelong member of the Haemophilia Society, though I cannot be sure as it was all a very long time ago.

43. I received a lump sum of £20,000 at some time in 1990, this being the Macfarlane Special Payment Trust 1st payment, and a further lump sum of £23,500 at some time in 1991, this being the Macfarlane Special Payment Trust 2nd payment. I received a lump sum of £20,000 from the Skipton Fund on 6 August 2004 and a further lump sum of £3,500 also from the Skipton Fund on 19 December 2016. I subsequently received further monthly payments of approximately £250 per month from the Skipton Fund between April and October 2017.

44. In addition, I received regular monthly payments, discretionary top up payments, and an annual winter payment from the Macfarlane Trust from April 2004 until the termination of these schemes in October 2017 and the inception of the England Infected Blood Support Scheme (EIBSS) in November 2017 whereafter such payments have thus far continued. At today's date, these regular monthly payments are £1,536 plus discretionary top up of £479 (for my HIV), £341.33 (for my Hepatitis C Stage 1) and a winter fuel allowance of £531, to be paid on 1 December 2019.

45. On a related theme, I know that many years ago I was offered a one-off payment from or through the government of the day, provided that I agreed to sign an indemnity against bringing any further claims, though I am quite certain this form of indemnity was subsequently withdrawn after both public and media pressure was brought to bear. Regrettably, I did not retain a copy of the signed document. However, it is highly likely that this one-off payment was one of those lump sums identified in paragraph 43 above, but I cannot be certain or specific.

46. I recall that the process of applying for financial assistance requires the completion of an annual census of income and accompanying proof in support. The difficulties or obstacles I face in applying for and obtaining financial assistance is the fact that I have to go cap in hand for the appropriate payments which I find embarrassing and frankly humiliating, particularly when I am obliged to disclose sensitive private financial information to some unknown bureaucrat.

47. The preconditions imposed on the making of an application for, or the grant of, financial assistance are set out on the EIBSS website and require: "a completed discretionary one-off application form; confirmation that all other sources of support available such as local authority grants, have been exhausted; two quotes for each item being requested; medical supporting letters/recommendations; and in all cases the applicant should check their eligibility with [EIBSS] before committing to any service or expenditure by reading the assessment criteria and paperwork required" when I would prefer to use the services of local, trusted, well known, long established, and recommended businesses.

48. I continually have to prove eligibility or entitlement to grants or payments through schemes supposedly intended to be "soft touch" applications, but, there never having been any clear detailed guidance or guidelines as to what exactly qualifies, the result is such that if I have needed something for which in all probability I might actually qualify, I have simply gone ahead and purchased without any recourse to these grant or payment schemes for possible contribution or reimbursement.

49. I feel resentment at the several devolved government schemes in Scotland, Wales and Ireland with their own separate levels of payment across the UK, when all victims of the contaminated blood scandal have been infected through the same source, namely dependency and use of contaminated blood or blood products supplied within the whole of the UK. The geography is immaterial as far as I am concerned.

Other Issues

50. Finally, having first grown up with inherited severe Haemophilia and its own debilitating problems, only then to be infected with HIV and Hepatitis C while still a young man, and with the shadow of vCJD hanging over me, I find it quite remarkable and take some comfort in the fact that I am still sane, have not at any time resorted to antidepressants or similar, and have not been driven stark raving mad. I am certain this is due to the devoted love, care and support of my late parents throughout their life.

Statement of Truth

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

Signed ___GRO-B

Dated ___9 May 2019___

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B
SCHEDULE OF EXHIBITS

EXHIBIT NO.	DESCRIPTION	PAGES
WITN0218002	Record of self-administered "home treatment" from 18/7/1976 – 30/11/2018.	4
WITN0218003	Letter from Dr Charles Hay to Dr F Preston and Dr Greaves dated 3/10/1985, Re: GRO-B	1
WITN0218004	Two letters from Dr K.K. Hampton to Mr GRO-B and Dr GRO-B dated 23/12/2004	3