Witness Name: GRO-B
Statement No: WITN1103002
Exhibits: WITN1103003-006
Dated: October 2020

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF GRO-B

I GRO-B, will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I was born on GRO-B and I live at GRO-B

2. This is my Second Statement. It should be read in conjunction with my First Statement dated 29th April 2019.

Section 2. How Infected

3. I was misdiagnosed with mild Haemophilia A at 6 weeks old by Dr Hill. I was infected with the Hepatitis C Virus (HCV) through contaminated Factor VIIII (FVIII) concentrate whilst under the care of Birmingham Children's Hospital (BCH). I was told in 1994 that I was infected with HCV. In 1998 at my first appointment at the Queen Elizabeth Hospital (QEH) in Birmingham I was told by Dr Wilde, to my absolute shock, that I had been misdiagnosed with Haemophilia at BCH.

4. My First Statement was made without the benefit of access to my medical records. As stated previously, my mother and I were told many years ago that my hospital records from BCH were 'lost'. I refer to Exhibit WITN1103003 being a copy of the UKHCDO record I applied for and subsequently received on 10th October 2020. The record is wrong. I am not a Haemophiliac and this was established by the NHS over 20 years ago.

5. I also refer to Exhibit WITN1103004 being a copy of the UKHCDO HCV data I received on 15th October 2020. The HCV data was sent to me after I made telephone contact with Mrs Lynne Dewhurst at UKHCDO with a number of questions to include querying the whereabouts of my HCV data. My HCV status was recorded through a look back exercise undertaken by UKHCDO last year. I would like to clarify that I did not give consent to any NHS service provider to disclose anything to UKHCDO and I did not give consent for my GP to provide the Oxford Haemophilia Centre (OHC) and/or the UKHCDO with my medical data.

6. My mother, sister and I lived in GRO-B for a couple of years (1988-1990). I was an outpatient under the care of the OHC for a brief time and recently received my medical records from that Centre. I refer to Exhibit WITN1103005 being a copy of Dr Hill's handover and early history provided by letter to Dr Rizza on 21st January 1988. I was treated with FVIII concentrate on just two occasions, the first being with 'Armour Factorate' in 1979 and the second in 1985 with 'Scottish Factor VIII' (referenced in my UKHCDO record as 'BPL').

7. I refer to Exhibit WITN1103006 being the balance of the medical notes sent by the OHC to include (at pages 4-6) HCV look back disclosure being made without my consent (and contrary to whatever 'implied consent' at page 6 might mean). I would also clarify that the only liver biopsy I have ever had was in 1998 and not 2004 (as apparently reported by my GP).

Section 3. Other Infections

8. I refer to my First Statement.

Section 4. Consent

9. I refer to my First Statement and I refer to Exhibit WITN113003. I had no idea that I had been tested for HIV in 1987. My mother was not aware of it and did not provide consent. I was told that I was being tested for HIV in 1994 and not before.

Section 5. Impact of the Infection

10. I am still dealing with the physical and mental health impact of being misdiagnosed with Haemophilia, infected with HCV via blood products, two year long courses of Interferon treatment and my father succumbing to GRO-B after believing he allowed me to be treated with infected blood products, while in his care. (Dr Mike Williams at BCH told us I would likely be dead by 30). Not to forget the social stigma this all carried at the time.

11. I have managed significant long term challenges with anxiety, depression and panic disorder. Throughout the past 20 years, I have regularly seen a counsellor and/or a psychologist for various treatment types. I have also required at numerous times, including currently, anti anxiety/depression medication.

12. Lessons have not been learned. Respect for patient privacy is still disregarded. The NHS is still causing me anguish after all this time. In 2019, BCH had reviewed patient records and were unsure if I had been tested for HCV. Even though I was under their care for 18 years, misdiagnosed as a Haemophiliac, infected with HCV and completed a year long trial of interferon. They told me in 1994 that they had infected me with HCV and I spent 1996 doing the Interferon trial.

13. Because BCH 'lost my records', Dr Jayashree Motwani of BCH incorrectly understood from the UKHCDO that I was under the care of the OHC. Dr

GRO-B contacted Dr Susie Shapiro at OHC who in turn invited me by letter to be tested for HCV, 10 years after being given the "all clear" and 28 years after being an outpatient at OHC. I really struggle to understand how they thought this was acceptable from a patient mental health view point.

14. I received this letter shortly after being married and finding out my wife was pregnant with our first child. To go through all that pain and uncertainty again is unacceptable. On receiving the letter, I didn't fully understand the reasoning behind Oxford contacting me, 28 years after being an outpatient. Having now seen the communication between the two hospitals, I feel compelled to be tested again for HCV and HIV.

15. I am made even more uncomfortable and greatly concerned that this data is held by a private entity UKHCDO and also my GP is freely giving incorrect medical data about me to NHS Haemophilia centres who are, in turn, emailing this to UKHCDO to be held on their National Haemophilia Database. The information is incorrect and I am not a Haemophiliac. This is unacceptable and greatly upsetting. Clearly not GDPR compliant.

16. On reading the UKHCDO data held on me, I can see that in the last 13 years, two Haemophilia Consultants have indicated I am at risk of vCJD: Prof FGH Hill in 2007 (Prof Hill conducted a HIV test without my consent in 1987 also) and Dr P Giangrande in 2014. Dr Giangrande has also documented I'm at risk from 1990-2001. The last blood products I received was in the mid 1980s, meaning this is incorrect information. Neither consultant contacted me to make me aware. I had the right to be informed.

17. Clearly the subject of consent and patient privacy is still an issue within these NHS Centres. This behavior does not put the patients right to privacy and consent at the the centre of practice or policy and procedure. This lack of adherence to data protection and duty of care to me the patient, has caused significant distress and removal of trust.

18. Again, I am full of anxiety and depression due to the mishandling of this situation. It feels cruel and unnecessary.

Section 6. Treatment/care/support

19. I refer to my First Statement.

Section 7. Financial Assistance

20. I refer to my First Statement.

Anonymity, disclosure and redaction

21. I confirm that I wish to apply for anonymity.

22. I do not wish to give oral evidence.

Statement of Truth

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

Signed **GRO-B**

Dated 21st Oct 2020