

ANONYMOUS

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Witness Name: GRO-B

Statement No: WITN2066001

Exhibits: WITN2066002-3 4 GRO-B

Dated: 14 August 2019

### INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 31 May 2019.

I, GRO-B will say as follows: -

#### Section 1. Introduction

1. My name is GRO-B (nee GRO-B) My date of birth is GRO-B 1969 and I live in GRO-B I am a part-time office worker. I am divorced and have a GRO-C son.

2. I intend to speak about my mother, GRO-B: M who passed away in 1984. In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

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3. I am not legally represented, I am happy for the Inquiry team investigators to assist me with my statement.
4. For personal reason I wish for my identity to remain anonymous.

### **Section 2. How Affected**

5. My mum was diagnosed with an auto-immune disease called hypogammaglobulinemia. From the end of 1972 onwards, my mum was treated with gamma globulin, a pooled plasma product. She passed away on GRO-B 1984, aged 50, when I was GRO-B years old. The cause of death on her death certificate is a) bronchopneumonia, b) bronchiectasis and c) hypogammaglobulinemia.
6. I am concerned that, due to the large number of gamma globulin treatments my mum was given during her life and the research I have done into the possibility of these types of blood products carrying infections, that she may have been infected with HIV or hepatitis.
7. I don't know for certain that she was. Mum's condition may have been entirely natural and she would have passed away at an early age regardless. But I would like the Inquiry to look at gamma globulin and whether it was a pooled plasma product responsible for transmitting any infections. If it was, it might affect a lot of people.
8. The medical information I detail below is largely based on my mum's diaries. My mum kept yearly diaries noting her visits to hospital, names of doctors, gamma globulin treatments, etc. I have her diaries from 1966 to 1982 (but not 1980).
9. I have tried to request copies of my mum's medical records from her GP, the hospitals where she was treated, the Medical Research Council and the access to records bureau. To date this has been to no

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avail, I have been told that the records have been destroyed. Therefore, I do not have any of my mum's medical records.

10. My mother was born in Wales. My parents knew each other from when they were young children. They later married in [GRO-B] when they were both in their 30s. My mother was very clever, she spoke German, French, Spanish and some Italian. Before marrying my father, she worked as a company secretary.
11. My dad was a [GRO-B] in the Army. After marrying, they relocated to [GRO-B] and lived there from 1964 to 1967. In [GRO-B] mum worked with the [GRO-B]
12. Whilst there, Mum had a skin graft operation, Dad told me this was a result of severe shingles, which would not heal. It would also appear that mum had another operation whilst in [GRO-B] however I do not know what for.
13. My parents returned to the UK in January 1967. My mum was admitted to the [GRO-B] from 28 August 1967 to 15 September 1967. I believe this was to have her appendix removed. I don't have any evidence of this, but recall dad saying she started having ongoing health problems after having her appendix operation.
14. I was born on [GRO-B] 1969 at the [GRO-B] [GRO-B]. My mother spent two weeks in hospital following my birth and may have been given blood at this time. My mother started having some issues when she was pregnant and the medical staff were keeping a close eye on her throughout the pregnancy. But as far as I am aware, it was a normal birth.
15. Five weeks after I was born, my mum started having a series of medical investigations done in relation to stomach problems and chest infections.

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16. Mum's main diagnosis was hypogammaglobulinemia, an immune disorder. I do not know whether she was born with it, or whether it developed later on in life.
17. Between October 1969 to August 1970, my mum received treatment from the [GRO-B]. She had three blood tests, an x-ray, physio, 14 hospital appointments, a cyst removed and a two-week hospital admission during this time. I am aware she saw Dr's [GRO-B] [GRO-B] and [GRO-B] at the [GRO-B].
18. My family moved to [GRO-B] in August 1970, where my mum saw a number of doctors at three hospitals – [GRO-B], [GRO-B] [GRO-B] and [GRO-B] s.
19. From 1970 to 1972, she saw Dr [GRO-B] at the [GRO-B] each month and had weekly appointments with the district nurse. She had at least one lengthy hospital admission in that time. She continued to have blood tests and x-rays taken. Mum also saw her GP [GRO-B] regularly.
20. She was diagnosed with glandular fever in February 1972. She lost a lot of weight, in July 1972 for example, she weighed 6 st 12 lbs. When she married dad she was about 10 stone, I have pictures of her looking fit and well. While living in [GRO-B] between 1972 and 1979, my mum also saw Dr's [GRO-B] and [GRO-B].
21. In December 1972, mum was referred to Dr A.D.B. Webster, a senior registrar of immunology at the Northwick Park Hospital in London. Further chest and skull x-rays were taken and she also had tests done on her stomach, as well as a bone-marrow biopsy.
22. Mum then started receiving intramuscular gamma globulin injections in 1972 at Northwick Park Hospital. She received an initial six doses in December 1972. She then received weekly injections from 1973 until June 1977, when they then began giving her double doses. From

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September 1981, she was given at least 21 gamma globulin treatments intravenously until at least December 1982 (she did not keep a diary in 1983 or 1984, she was very ill and unable to continue with her diaries).

23. At the Northwick Park Hospital, Dr Geoffrey Lister Asherson treated my mother from 1976 to 1977, during this period of time her gamma globulin doses were doubled. Mum also continued seeing Dr Webster until at least 1977 and she also saw Dr Platts-Mills in 1978.

24. On occasions Mum would have a major reaction to the gamma globulin, which, she documented in her diaries. When this happened, she would go to either Northwick Park or one of the three hospitals in

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for her next dose.

25. In terms of mum's symptoms generally, I remember her coughing all the time. Whenever we walked somewhere, mum would be so slow, coughing and bringing up phlegm. On occasions she also suffered with very swollen lower legs.

26. As I have already stated, mum lost a lot of weight. She became very thin at times. I have a photo of her and I when I was 11 and Mum looks physically smaller than me. When she passed away, mum weighed around seven stone or less.

27. Mum was quite physically weak. I never remember her playing with me. She was always at the sink washing, or cooking. I don't think she had much energy for interacting with me, or anyone else. Mum had pneumonia on at least eleven occasions and several bouts of bronchitis and chest infections.

28. Towards the end of her life, mum was bedridden, I'm not sure for how long exactly. She stopped keeping a diary because, I guess, what would you write about when you're dying and you know it?

29. I recall she had oral thrush at times, this may have been due to antibiotics she was prescribed. Mum also had something on her legs,

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which I thought were broken veins, this covered large areas. Mum also received vitamin B12 deficiency neocytama<sup>en</sup>n injections from 1973 onwards.

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30. We did not have any assistance caring for my mum when she was bedridden. My dad was her carer, running the house and also raising me. Before he went to work in the mornings, my dad would make up a flask of soup, tea, a tray of food for mum. He would wash her and do everything for her.

31. Mum was on an oxygen tank. I would help mum with physio to try and drain her lungs. She had a commode next to the bed, and a small TV to watch.

32. A charity called Cross Roads arranged someone to assist with the ironing. We also had a stair lift installed and the occupational therapist gave her a "grabber". Dad also changed the kitchen for her to make it more user friendly, however she was too ill to really make use of this which was a shame.

33. Mum passed away at home on GRO-B 1984, the day after my dad's GRO-B birthday. That morning after breakfast, I went into her room and she looked like she was sleeping. Dad told me to go and get the neighbour.

34. When I came back, mum was still alive. I knelt on the bed with her and told her things like "you don't have to suffer anymore, mum." Then she stopped breathing. I still have my diary from the time, and the entry for that day is "mummy died." It was very sad.

35. Her funeral was on GRO-B 1984. The man who organised the funeral was lovely. He also took care of my dad's funeral in 2015.

36. When mum passed away, Aids was in the news all the time and the advertising campaign with the grim reaper was on TV. Even in the early 1980s, perhaps mum read a newspaper article or watched the news

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about the risk of blood transfusions. I do wonder whether mum ever had questions about this or spoke to someone about it, like my dad or her GP or other doctors. Mum was very intelligent and she would have known her treatment came from blood; she was very up to date with current affairs.

37. I wonder what mum and dad would have done if they had asked about it. I suspect even if she knew, mum would never have said a word about it because of the stigma around Aids.

38. As far as I knew at the time of mum's death there was no concern that her death might have been related to Aids or hepatitis. In my 20s, I read a travel book that mentioned protection against hepatitis and also gamma globulin, however it had later transpired that the gamma globulin could transmit HIV.

39. This was the first time I started thinking about my mum's treatment and her symptoms, some of which are similar to Aids. I mentioned it to dad but he didn't seem shocked, or react as though he had any inkling of that.

40. I have since done some research into hypogammaglobulinemia and gamma globulin. Gamma globulin was originally seen as a wonder product and used as a prophylactic against measles, rubella and other infections. In the 1970s, people said it was made from "small pool plasma" and it was thought to be very safe.

41. However, the Penrose inquiry said the injectable form of gamma globulin was only made safe in the late 1990s. I have also located an article on intravenous immunoglobulins written by Dr Webster, one of my mother's treating doctors. This article was published in the British Medical Journal in 1991 and states "*a few patients probably acquired HIV from contaminated intravenous immunoglobulin at the beginning of the AIDS epidemic, before donors could be screened.*" I produce this article as exhibit **WITN2066002**.

**Section 3. Other Infections**

42. I am not aware of any other infections my mother had.

**Section 4. Consent**

43. I do not have any criticisms of the medical care and treatment my mum received. I don't recall my parents having any concerns about the care she was receiving, they felt it was the best available at the time. Mum would have consented to her treatment; she didn't really have a choice due to her condition. At the time there was no talk of contaminated blood. Gamma globulin, as a treatment, had several years of provenance.

44. I do wonder though whether mum's treatment was part of a broader research project. I say this due to the dates and nature of her treatment and then corresponding research publications by some of her treating doctors at Northwick Park. In particular, Dr Webster and Dr Asherson published articles and case studies regarding the same medical issues my mum had, dating back to 1974.

**Section 5. Impact**

45. I felt my family and I were defined by my mum's health problems. We didn't have days out as a family, I could only go for days out with the neighbours.

46. We could only go on holidays for less than a week because mum had to have her weekly injections. I remember her taking an injection with her when we went on a holiday so she could give it to herself, but she had a bad reaction when she did this and did not do it again.



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47. Holidays usually involved going to the shops several times on the bus, then going to the surgery for mum's appointments. I would sometimes take mum's samples to the GRO-B by myself.
48. I feel mum was forgotten in a way. Other family just say she had poor immunity, they don't fully understand the severity of the decline in her health, her lack of energy, the weekly treatments she had to get, all the physio she needed.
49. I feel sad for mum because she was very clever. I think she would have wanted to continue with her career but she wasn't able to consider going back into the workforce because she was so ill. I hadn't read mum's diaries until preparing for this statement. I was shocked reading them, as nearly the whole of each diary is filled with doctor visits, nurse visits, hospital visits.
50. It's hard thinking about how someone might have been if they hadn't been so ill. It would have been so nice to be able to talk to her about work and my studies. She was an educated and sensitive person. I wonder what my relationship would have been like with her?
51. After she passed away, I became the girl whose mum had died. It is unusual not to have both your parents alive when you're young. No one teased me, but I did feel different.
52. I threw myself into academia, I studied History at Oxford University where I obtained a 2:1. But studies didn't set me up for life – I didn't have a mum to talk to. My son also never got to know his grandmother.
53. Dad lived until his eighties and never remarried after mum passed away. He told me he wouldn't have been able to keep going if he didn't have me to look after. A doctor told mum she shouldn't have any more children, I think dad would have liked to have another.

**Section 6. Treatment/Care/Support**

54. I was never offered any counselling when my mother died. If I had been, I probably would have taken it. I'm not sure whether my dad was, he might have.

**Section 7. Financial Assistance**

55. Apart from the assistance we received from Cross Roads with the ironing when mum was unwell, we never received any form of financial or other support.

**Section 8. Other Issues**

56. In the course of my research into hypogammaglobulinemia and gamma globulin, I came across a number of academic articles that may be relevant for the Inquiry. I produce this bundle of articles as exhibit **WITN2066003**.

57. I am also aware of two HMSO reports published in 1971 and 1979 on hypogammaglobulinemia in the UK and the uses of gamma globulin.

58. I did write to the UK Research and Innovation asking for information as to whether they had any of mum's records. I received a letter dated 23<sup>rd</sup> July 2019, in which their response is recorded.

59. Briefly they say that *'The MRC did identify that it does hold secondary information about research conducted at the Clinical Research Centre at Northwick Park, including secondary information about the research programme of the Division of Immunological Medicine (headed by G.L. Asherson) ...The reports for the CRC – including the reports related to*

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*hypogammaglobulinaemia research – have been published and are held at the British Library. The reports that have been identified are:*

*1970/1 and 1972/3. Scientific report – Clinical Research Centre. Harrow: Medical Research Council 1972-1974.*

*1974/5 and 1976/7 Biennial report / Clinical research Centre, Harrow. Medical Research Council 1976-1978.*

*1978/9 – c – 1990. Report. Clinical Research Centre. London. Medical Research Council 1979. I produce this letter as exhibit WITN2066004.*

**Statement of Truth**

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

Signed

GRO-B

Dated

14 Aug 19.