

Witness Name GRO-B

Statement No: WITN1717001

Exhibits: 0

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B and I live at GRO-B
GRO-B My date of birth GRO-B
2. I write this statement on behalf of my mother GRO-B date of birth
GRO-B who wants to make this statement on behalf of her late husband
(my father) GRO-B: F date of birth GRO-B My father died in
GRO-B as a result of the infections.
3. My mother is now in a residential care home suffering with GRO-C I have
power of attorney for my mother and I am her next of kin.

Section 2. How Affected

4. My father was a mild haemophiliac with haemophilia A. Before GRO-B he was
treated with Factor VIII (VIII) in GRO-B, GRO-B and GRO-B (BPL, Factorate, PFC) at
the GRO-B and he was under the care of
haematologists GRO-B and, subsequently, GRO-B Unfortunately, I
have not been able to obtain his hospital records and I am relying on the

ANONYMOUS

information provided by United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO). Both the [GRO-] and [GRO-B] are ignoring requests for records.

5. From some handwritten notes of my father's I gather he was informed that he had Hepatitis C (Hep C) in [GRO-] and had been tested in [GRO-B]. I believe he was under the impression that mild haemophiliacs were a nuisance to the hospital at that point, from which I believe the hospital were trying to deter patients from asking too many questions. I do not know what, if any, information he was given beforehand about risk of being exposed to infection.
6. I do not know what information was provided to my father or if adequate information was provided to understand and manage the infection.
7. My father was infected with Hepatitis B (Hep B) and Hep C through contaminated FVIII blood products. He died in [GRO-B] as a result of the infections.

Section 3. Other Infections

8. I do not know if my father contracted any other infections other than Hep B and Hep C.

Section 4. Consent

9. I have no details about him being tested other than those given above, and believe that it was possible he could have been treated or tested for the purposes of research. I cannot say if he was treated or tested without his knowledge or consent. I also doubt that he was fully informed about the treatment received, because of the scant information provided to us by the hospital.

Section 5. Impact of the Infection

10. Physically, the impact on my father was huge. He was slowly deprived of his health and vigour and was forced to take early retirement. Formerly a strong,

vigorous person, he became increasingly less mobile, walking with a stick for any journey beyond a few yards. The infections caused, in addition, bouts of jaundice, exhaustion, and cirrhosis with consequent portal hypertension, oesophageal varices (which necessitated hospital in-patient treatment on more than one occasion), and oedema to his abdomen which had to be regularly drained at the [GRO-B].

11. My father was put on the transplant list and provided with a bleep. When the end-stage liver disease set in he became an in-patient at the High Dependency Unit at [GRO-B] over the spring and summer of [GRO-B] where he waited for a donor liver to become available. When one was ultimately procured his disease was so far advanced that, despite the operation taking place, there was uncontrollable bleeding and he died a short while later without regaining consciousness.

12. I believe he found the infections difficult mentally. Having had his life saved [GRO-B] [GRO-B] by [GRO-B] blood products at the [GRO-B] [GRO-B] under the care of [GRO-B], I believe it must have been additionally hard to deal with the irony of being infected and made ill by the administration of treatment [GRO-B] [GRO-B]. He was a long-serving member of the Haemophilia Society and I believe was part of the campaign to persuade the government to deliver heat-treated FVIII. I know that he was angry about what he saw as unreasonable delays and prevarications from various Secretaries of State. I also know that he was frightened about how the Hep C might progress, and frightened of dying.

13. He did begin treatment with Interferon, although I cannot recall the date and have been unable to secure his medical records, but the side-effects were too severe to be compatible with continuing work and he gave up the treatment before the end of the course. With no savings it was impossible for him to provide for his family without working and so he gave up the treatment. This will have deprived him of the opportunity of a cure and also, I believe, must have had a strong effect on his mental health. My father was not one to share

his emotions and fears with anyone but his wife, and, unfortunately, she is now unable to provide any account of that time.

14. I was only visiting my parents every few weeks at this time and so can provide no detail but I believe his social life was severely curtailed as the infection progressed and his illness meant he and my mother were no longer able to visit me and he became effectively house-bound.

15. It is hard to speak for my mother as both my parents tried to shield their GRO-B from worry as much as possible. I know that she was angry and participated actively, after my father's death, in campaigns lobbying MPs for information and redress. I believe she suffered great grief and stress as she became his carer and I witnessed one incident which shows this: she was responsible for providing my father with a neutropenic diet and one day he ate a strawberry straight from the plant. I saw her horror, anger and tears, and know that she blamed herself for this event which led to a period for my father as an in-patient at the GRO-B.

16. I also sat beside her as we waited during the transplant operation and recall her distress as the wait went on and on. My mother had never shared her fears, or wept in front of me but her grief at my father's death was devastating and long-lasting. She was too distressed to attend his funeral. After my father's death her social life became more limited and they clearly did not enjoy the retirement together which they could have hoped for. My father's early retirement diminished the pension my mother received.

17. I have no information to give about my father's attitude to the infection but can say that my parents were unlikely to share medical details of their lives. GRO-B his haemophilia was well known to friends, work colleagues and the local community.

18. My GRO-B interferon treatment was kept a secret from our mother and the rest of the family, and it became very difficult to provide plausible excuses for GRO-B ill health. My GRO-B infection and GRO-B wish to keep GRO-B condition a secret also, I believe, took its toll mentally on GRO-B GRO-B who has GRO-B suffered

continuing mental health problems for many years. At a very young age [GRO-B] had to take on caring responsibilities whilst being, I believe, enjoined to secrecy, and I believe [GRO-B] school work and mental health suffered as a consequence. It is a testament to the strength of both of them that [GRO-B] has now been able to attend university.

19. My [GRO-B] understandable desire to keep [GRO-B] infection between us means I have kept my worries about [GRO-B] to myself for years and have had no support to deal with this. For a long time I worried that, as well as having lost my father, I would also lose my [GRO-B] and have to give up work to look after [GRO-B]

20. My whole life has been coloured and defined by my father's haemophilia. I was conceived after the [GRO-B] to my father, which should have been fatal – I owe my existence to the blood products and to [GRO-B] [GRO-B] – and I have marked my life by his treatment, ill-treatment, death and subsequent campaigns for justice.

21. During his decline and last hospitalisation in [GRO-B] I travelled daily to visit him after each day's [GRO-B], working on the train and at his bedside. From the end of [GRO-B] my mother stayed with me and we travelled daily together to see him. I was with her when he died, helped her with the formalities, arranged the funeral and was the chief mourner when she was too ill to attend the funeral. I continued to support her emotionally and physically over the years, taking several large chunks of unpaid leave from my job [GRO-B] to do so, and taking on some of the tasks that my father would have done. I handled most of the dealings with the Skipton Fund for her, filling in forms and arranging bank accounts etc., and now communicate with the EIBSS scheme on her behalf. Finally I became her carer as she slid into dementia. Although I did these things willingly it has not been without considerable financial and emotional cost, and to the detriment of my own health – at one time I had depression severe enough to warrant medical treatment and a [GRO-B] absence from [GRO-B]. Although [GRO-B] was supportive, that, and the absences I took to care for mother, were obviously not well received by the

County Council and affected my employment record, causing me further anxiety.

22. My mother was determined that GRO-B would not suffer in the way my father had done, and she told me at the time on more than one occasion that she vocally demanded of doctors at the GRO-B that only heat-treated FVIII be used for her. Neither GRO-B nor I told her that this had made no difference, and we kept GRO-B infection a secret from her. I have financially supported GRO-B for years as GRO-B hepatitis infection, and the lasting effects of GRO-B interferon treatment, meant that GRO-B is unable to work full time. When I was working I provided half my salary per month to GRO-B, and now that I have had to take early retirement because of ill health I send over a quarter of my GRO-B to support GRO-B. I continued to support the Haemophilia Society campaign for several years, lobbying parliament, writing to MPs, presenting lilies at Downing Street and providing interviews to the press until my strength failed along with my belief in any kind of positive result.

23. I miss my father dreadfully – it was ten years before I could speak his name without tears.

24. For myself, I just wanted someone to take responsibility and to say that they were sorry.

25. My father had to take early retirement due to cirrhosis and I believe his progressive disability had a detrimental effect on his prospects for promotion. Early retirement obviously depleted the amount of pension he was able to draw for himself and to pass on to my mother.

Section 6. Treatment/care/support

26. His handwritten note suggests that yes, he did experience difficulties obtaining care and support.

27. I was not offered any counselling or psychological support.

Section 7. Financial Assistance

28. My father never received any financial assistance, he died in GRO-B before such schemes existed. My mother received three lump sum payments from the Skipton Fund: 1st stage ex gratia payment of £20,000 in GRO-B, 2nd stage ex gratia payment of £50,000 GRO-B and a Bereavement payment of £10,000 in GRO-B.

29. She currently receives £500 per month and received a winter fuel payment of £519 on GRO-B from the EIBSS discretionary support scheme. I am currently in possession of a new claim form from EIBSS for the coming financial year. I have not yet applied on her behalf as I do not have details of what her Civil Service Pension will be for the coming year.

30. I believe that it was because the death certificate listed cirrhosis and Hep B and C that I did not experience difficulty in accessing payments for my mother. However, finding out about the payments and entitlement from both the Skipton Fund and EIBSS has not been easy and I have relied on my GRO-B involvement with campaigning groups to know when, and to whom, I should apply.

Section 8. Other Issues

31. My father was unable to be involved in any earlier litigation as he was unable to obtain legal aid.

Anonymity, disclosure and redaction

32. I confirm that I do wish to apply for anonymity.

33. I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-B

Dated

28 February 2019