Witness Name: GRO-B

Statement No.: **WITN2315002**

Exhibits: **WITN2315003 - 011**

Dated: 20 June 2019

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF GRO-B

I provide this further statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry. I have provided a written statement to the Inquiry, dated 28 February 2019. I am providing this further brief written statement in order to add some matters to my previous statement which

relate to the questions asked in the request under Rule 9 of the Inquiry Rules 2006. I am doing this as since my first statement was completed I have been able to access my late mother's medical records. These run to over 9,000 pages but they have been helpful in providing detail which has refreshed my memory about events. My mother was in certain respects quite secretive about her infection with hepatitis C and so there were things in those records of which I was not aware but which I would like now to tell the Inquiry about, as I have discovered them from the records.

2. In the first place, my mother died on GRO-B 2012 and not in 2011 as in said in my statement. I have now seen her death certificate. Though I was right that the main cause is listed as pneumonia, it also lists and cerebrovascular accident, dementia and von Willebrand's disease ("vWD"). The certificate does not list hepatitis C or cirrhosis and I think that this did play a part in her death and should have been recognised there. As I read it, they have just listed things that are associated with old age.

3. I would also like to add that I have a good knowledge of vWD. I have lived with the condition myself since the age of 5. The condition affected my mother and now affects my daughter. In addition, I have worked in a laboratory as a technician in a number of different hospitals, including at the RIE haematology laboratory. I have therefore done a number of lectures on the subject of vWD to students over the years. In understanding my mother's case and indeed mine, it is important to realise that the bleeding which occurs in patients who suffer from vWD (type 1 or type 2) is not the same as in individuals who suffer from haemophilia A or B. Whilst many of patients suffer joint bleeds, patients like my mother and me (with type 1 or 2 vWD) bleed more through our mucus membranes. This leads to problems with things like nosebleeds, bruising and heavy periods but, more particularly in our case,

internal gastrointestinal bleeding which can (and did for both of us) lead to both acute and chronic anaemia.

4. As far as treatment is concerned, individuals who suffer from vWD lack the vW factor which is an essential part of the coagulation cascade which is needed to control bleeding. The vW factor works as a delivery mechanism of the factor VIII protein which is necessary to make the blood clot. The absence of the vW factor therefore means that the factor VIII protein is not delivered as it should be, with the result that the blood does not clot. Now my replacement therapy (which I discuss further below) involves replacement of the vW factor (Haemate P and then Voncento). At the time my mother was being treated, she would receive cryoprecipitate for bleeding which had the dual effect of replacing the vWF (which would have been part of the cryoprecipitate) and the factor VIII which it delivered to the coagulation cascade. As her treatment records show, it was also possible for her to be treated with factor VIII concentrate which would have the effect of delivering the "undelivered" factor VIII protein to the cascade.

Section 2. How infected

5. I would like to add in some more detail about the treatment which my mother received and the timing of her possible infection. Her records show that she did get treatment with cryoprecipitate on a number of occasions in the 1970s and 1980s. I mentioned in my first statement that she had a fall on the stairs which led to an ankle injury in around 1981/ 82 (paragraph 4). I have clarified from her records that this occurred in October 1981. She was treated with cryoprecipitate. She then developed a haematoma of her thigh in around

November 1982. This ultimately led to what I think from her records was the one occasion when she received factor VIII concentrate before I now understand them to have become safe for hepatitis C in 1987. I do have a recollection of the circumstances in which this occurred. I remember this as I was working in the haematology laboratory of the RIE at the time. I remember that Dr Ludlam (who was then my boss as well as my and my mother's doctor) came to me in the lab and said that of someone has a hot thigh then that is a haematoma. He was referring to my mother and suggesting that I should have detected the haematoma. I remember thinking that it was unusual to suggest that I should have been checking my mother's thighs.

6. My mother was initially treated for the after effects of the fall and for the haematoma in her thigh with cryoprecipitate. In early 1983, he was given factor VIII concentrate in hospital at that time. I exhibit this under **WITN2315003** I was approached by the medical staff and told that I could take her home and inject her with the concentrate. They asked me if I wanted to do that as I had performed phlebotomy duties in several haematology out-patient clinics over a number of years. I was told that this would be a good way of her getting out of the hospital. I took the products and injected her at home as they had suggested. I only did this a couple of times as my mum's veins were not good and I struggled to give her the treatment. Therefore she had to return to the hospital to have the factor VIII given on an out-patient basis. Her treatment carried on for some time, over February and into March 1983. By 21 February 1983 she had had had "multiple factor VIII infusions". I exhibit this under **WITN2315004** I was certainly never advised that there was any risk associated with the product or that it carried any different risk from the product she had had. I do not think that mother received any such advice either. She was the kind of person who would just do what she was told by the doctor, as I said at paragraph 4 of my

first statement. Of course, I now know that I may have injected her with the product which infected her with hepatitis C.

7. I would like to add in some more detail about the time at which my mother found out about her infection with hepatitis C. In my previous statement (paragraph 6) I had thought that this was around 1983. In fact I now think that was inaccurate. I referred to a meeting which I attended at paragraph 7 of my first statement. I attended with both of my parents. I think that that meeting may in fact have taken place in late 1984, shortly before (as her records reveal) my mother was tested and found to be negative that virus. That created a knowledge on her part of the risk of virsues from the treatment. She was worried about that and, as the letter from Dr Ludlam at that time states, required to be reassured. I note that at that time she was told that the risk of sexual transmission from an infected man to an uninfected woman was thought to be less than the risk of sexual transmission in the opposite direction. I exhibit this under **WITN2315005**.

8. In fact, after looking at my mother's records, it seems that she was told about her hepatitis C infection in around 1993. The precautions I refer to my parents being told about in paragraph 8 of my first statement relate to being told about the infection in 1993.

9. In a letter from a consultation of 22 September 1992 from Dr Dennis to my mum's GP, it states:

"She says she has felt more tired than usual over past few months but puts this down to her increasing age…I have taken her routine bloods and arranged to see her in a year."

I exhibit this under **WITN2315006**.

Her records show that her bloods which had been taken were tested was tested on 22 September 1992. I exhibit this under **WITN2315007**. It was reported on 1 October 1992 that she was Hepatitis C positive. There is a note from January 1993 which states that she had tested positive for Hepatitis C and that this should be discussed with her. I exhibit this under **WITN2315008**. There is a letter in her records date 15th September 1993 relating to her being told about her infection. It seems that she was not told until that time, around a year after she had fisrst tested positive and despite the fact that her original symptoms of fatigue may well have related to the diagnosis. It notes that she did not appear alarmed but this is not surprising as she appears to have been given little if any, information about what the diagnosis meant. I exhibit this under **WITN2315009**

Section 3. Other Infections

10. I make come comments about the possibility that might have been exposed to a risk of vCJD below.

Section 4. Consent

11. I would like to add some further detail and analysis to the evidence I gave at paragraph 12 of my first statement. I had an amniocentesis when I was pregnant with my daughter in 1990 and also had to have an emergency Caesarean section when she was born in 1991. As I have said in my first statement, Professor Ludlam was very keen that I should have a factor VIII concentrate in advance of having these procedures. I was very wary about having any such treatment, as I have said and was insistent that I should not be given them in advance but that the products should instead be available on stand-by if absolutely

necessary. I had thought that this was because I was aware of my mother's hepatitis C diagnosis at that time and so was worried that I too might become infected with that virus. On reviewing my mother's records, I now recall that she did not find out about that infection until around 1993. I was, however, wary about the risks of infection from receiving factor VIII concentrate because of the risk (which my mother had discussed with me) that she might have contracted HIV (as discussed above) and also my awareness from my work in the laboratories that we had to handle blood which was marked high risk. This made be very wary about the risks from factor concentrate as and I wanted to avoid having to have them. That has continued to be my view about these products until recently (as I discuss below).

12. As I said in my first statement, I was told by Professor Ludlam that the factor VIII concentrate was safe at that time. I now understand that this may be have true, in the sense that Scottish Factor VIII concentrate had been subjected to an effective heat treatment regime since 1987 so as to remove the infection risk from hepatitis C. I did not know that at the time. I was scientist and professor Ludlam knew me from when I had worked in the RIE laboratory (when he had been my boss) and also as a patient over many years. He simply told me that the products were safe. I think that he should have explained to me what had happened with the heat treatment developments. He knew I would have understood. If he had I would have been more reassured. Instead, he just expected me to accept his word that they were "safe". That made me continue to be concerned that I was not prepared to take the concentrate as cover for the surgery. Of course, I now also know that to say that the product was "safe" is in fact never really true anyway. He must have known that the products tended to become infected with various viruses which might not have been known at that time. My mother's records show that she was contacted as having

ben at risk from vCJD as she had received concentrates between 1981 and 2001. Although I accept that that could not have been known in 1990/ 1991 when Professor Ludlam told me that the product was "safe" there was still a risk that such a virus may be discovered later. As it happens I too would have been put at risk of vCJD had I taken the factor VIII concentrate at that time. I would have lived with the uncertainty as to what that might have involved.

13. I am also aware that blood from patients would often come to me for testing with "high risk" labels on it while I worked in the RIE (which I left in 1983). Although I cannot remember if this was specifically related to the blood of bleeding disorder patients, I did do work on their blood which would have included testing for factor VIII levels. I am aware that certain technicians were involved at that time in doing research on blood for Dr Ludlam but I was not involved in that.

Section 5. Impact

14. I mention that my Mum tried Interferon treatment once and thought that this was in the late 1980s (paragraph 19 of my first statement). Her records show that this was in 1995. She could not tolerate this and never wanted it have treatment again as a result. This obviously meant that her liver condition progressed to cirrhosis without treatment.

15. As I have said above, I have always tried to avoid having concentrate products myself. This is because I have always been concerned about the infection risks, both before my mother's diagnosis with Hepatitis (as discussed above) and after it. I have therefore avoided having any such products and was only prepared to have such products when I

started to have gastrointestinal bleeding myself in around 2008 but avoided treatment using blood products until February 2013 when I had my first blood transfusion and first HaemateP infusion on the same day. I have since had to start taking these products prophylactically to deal with my GI bleeding. I am left feeling that these products never come without risk and that, like my mother, I may find out that they are infecting me or harming me at some later date.

Section 7. Financial Assistance

16. My Mum clearly spoke with Professor Ludlam about compensation. It seems that she had been told after having spoken with the Scottish office that they would only offer compensation at that time to people who had bene infected after 1st March 1988. I exhibit this under **WITN2315010** Her medical records also contain a letter which she received from the government about possible compensation. Although this letter purports to be to her and about her case, it talks about haemophilia and not vWD. I also suggests that patients like her needed factor VIII treatment and that it greatly improved her life expectancy and quality of life, which in her case is simply not accurate at all. I exhibit this under **WITN2315011**

Section 8. Other Issues

For the sake of clarity, the reference to what was said at the Penrose Inquiry at paragraph 12 of my first statement was to what was aid at the day the report was launched. It was a terrible day and I left the auditorium feeling as low as I ever have. I remember walking through central

Edinburgh and seeing a homeless man. I felt so bad. I approached him and gave him ten pounds and that something good had to come from such a terrible day.

ANONYMOUS

Statement of Truth

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

Signed GRO-B

Dated 20th June 2019