Witness Name: GRO-B
Statement No.: WITN2302001
Exhibits: none
Dated: 3rd September 2020

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 15th May 2020.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My maiden name is GRO-B. My date of birth is GRO-B 1982 and my address is known to the Inquiry. I am married to my husband GRO-B and we have been married for six years. I am currently employed as a GRO-B and have been in that role for twelve years. I intend to speak about my father GRO-B: F who was born on the GRO-B 1964 and passed away on GRO-B 2000. I will speak in particular about the nature of his illness, how the illness affected him, the treatment he received and the impact it had on his and our lives together as a family.

2. I would like to remain anonymous for this statement for privacy reasons.

Section 2. How Infected

3. My Dad was a very private man, he liked to keep himself to himself and privacy was important to him. He was always very family orientated, everything he did was for our family. He was a hard worker and had a lot of drive in that way. My Dad was a very loving person, he always made me and the rest of the family feel loved. He was the type of person that made us all feel safe and protected. I had a really good relationship with my Dad before his treatment. We enjoyed going to football games together every now and again and we got on so well because we basically had the same personality, we were very similar people. My Dad worked as a GRO-B for a living and was in that role over twenty years.

4. My Dad had haemophilia A, which was mild. He would have been treated at Yorkhill Hospital, Glasgow for his haemophilia when he was child and he was moved to the Haemophilia Unit at the Glasgow Royal Infirmary when he was sixteen. I could not say who was in charge of Dad's care at Yorkhill but is was a Dr Tate in charge of his care at the Glasgow Royal Infirmary. He would receive Factor VIII to treat his haemophilia. As far as I can remember, my Dad was infected with hepatitis C when he was thirteen, I would not be able to say exactly what date this would have been. He had been in a fight at school which had caused his face to swell up considerably. He was taken to Yorkhill Hospital to be treated and that was where he was diagnosed with haemophilia A and received Factor VIII to treat his facial injury. We believe it was this treatment that led to Dad contracting hepatitis C because the batch numbers for this first treatment have never been found by the hospital, so they told us they assume it must have been this first treatment that led to the infection. I cannot remember exactly when we were told this.

5. I have spoken to my Gran, my Dad's mum, about what happened and I know that neither her nor my Dad were ever informed about any potential risk of infection from receiving these blood products.

6. My Dad was diagnosed with hepatitis C in 1995, I could not say exactly what date this was. He was asked to come into the Glasgow Royal Infirmary with my Mum for what they thought was just a normal check-up appointment regarding his haemophilia. The appointment was actually to give him his diagnosis for hepatitis C but they had not told him that beforehand. My Dad was not aware that he had been tested for hepatitis C either, they told him at the appointment that they had performed the test on a blood sample they had previously collected. I could not say who they spoke to that day but my Mum remembers that they spoke to a doctor and a student doctor. The Royal Infirmary Haemophilia Unit was being renovated at the time so when my Mum and Dad arrived, they were taken into a cleaning closet for the appointment. In this cleaning closet was where my Dad was told he had contracted hepatitis C. They gave no indication at that appointment how long my Dad could have had the infection for.

7. Mum and Dad were given almost no information at all. They were told Dad had contracted the infection, then they were told briefly about risks of cross infection and they suggested my Mum should be tested for hepatitis C, and that was basically it. They were given three information leaflets by the doctor and that was the only real information they received that day. I remember Mum telling me one of the leaflets was about drug use but I could not say what the other two were about. They were given those leaflets and told they could arrange a follow-up appointment if they wanted, that was all. Dad left that appointment without really knowing what hepatitis C was.

8. The information Dad was provided with at that appointment was not adequate to help him understand or deal with the infection in any way.

9. I believe the information about my Dad's infection could have been given to him much earlier than it was. I know that my Dad was tested for HIV and hepatitis B in 1988, he was not informed he had been tested for these infections. I feel they should have found something when doing those blood tests and he should have been monitored more closely from that point on. I know that there wasn't a lot of information about hepatitis C at that point but I

think they should have seen that he was at risk during those tests and he should have been followed up on. I don't feel he was given that care, I think they saw he didn't have HIV or hepatitis B and just left it at that.

10. The way my Dad was told about his infection blindsided him. He just thought he was going in for a normal appointment and then they gave him some of the worst news possible. He had absolutely no idea what he was walking into that day and they did not prepare him for it. The infection was something that was going to change all of our lives and they did not give the care or after care you would expect for a situation like that. He was told he had hepatitis C and then he was sent on his way.

11. At that diagnosis appointment, if you can even call it that, my Mum was told that she should get tested for hepatitis C as a precaution. They then gave a very brief outline of cross infection, things like not sharing toothbrushes or using condoms but there was nothing explained in depth about cross infection.

Section 3. Other Infections

12. Dad received a letter in 2003 informing him that might have vCJD but when Dad got that letter, it was during his second course of treatment for hepatitis C. He just said, "*Is there anything else they can do to me?*" tore the letter up and threw it in the bin. I could not say what else the letter said. During one the Inquiry hearings, we found out that one of the batches of blood products that had been infected with vCJD was a batch that my Dad had received. He was never tested for it but there was a very high chance that he did have it.

Section 4. Consent

13. My Dad was tested without his knowledge and consent on two occasions that I know of. Once for the HIV and hepatitis B screening in 1988 and once for hepatitis C. I remember that when he went in for his diagnosis for

hepatitis C, they told him that the test had been done using a previous blood sample, which he was completely unaware of.

14. I also believe that my Dad was tested for research purposes. We have since found out that when my Dad was thirteen and first received Factor VIII, he actually did not need to receive blood products to treat that injury. It was not that severe an injury and did not warrant him receiving Factor VIII. We believe there were a number of occasions where he received blood products unnecessarily and that he was given those treatments as part of some sort of research.

Section 5. Impact

15. Before he started his treatment, you wouldn't have even known there was anything wrong with Dad, he was just his normal self. I was still quite young before Dad was treated and the infection was never something I noticed affecting him before that. He would still be going out to work and pulling twelve hour shifts every day to provide for his family, he was a hard worker. The infection didn't really affect his day to day life at all, mentally or physically, before his treatment. Life just went on pretty much as normal.

16. I am not aware of any further medical complications or conditions being caused by my Dad's infection.

17. Over the course of the infection, my Dad went from being a normal hard working dad to being a living nightmare. He just changed so much as a person. At the end of the twelve month course of treatment in 2003, Dad was told that his treatment had not worked. A month later he had left the family home to live with his Dad. He left because he just wanted to drink alcohol, he wanted to die. He knew what he was doing to us and he didn't want us to see him destroy himself. He ended up becoming an alcoholic, we didn't know where he was day to day and we always worried we would get a phone call saying he had died.

18. Dad was always someone who like to look his best, he liked having designer clothes and nice shoes, the whole thing. Also his hygiene levels used to be off the charts, he would shower morning noon and night and like to keep himself looking smart, he took pride in his appearance. After he left the family home he went from that, to someone that smelled, someone who would wear the same clothes for days on end, he looked homeless. He had completely given up on life. People that knew my Dad would say to us that they had bumped into him and they couldn't believe the difference in him. He went from a driven, hardworking family man to someone who had completely given up on himself. That's why he left, because he didn't want us to see him get as low as he got. He wouldn't let us or anyone else help him, I feel that when he was told his second round of treatment was unsuccessful, that was his death sentence. He died five years after he moved out of our home.

19. Dad had his first round of treatment around 1997/1998 through the Glasgow Royal Infirmary. It was Interferon he was given but the treatment was stopped after twelve weeks because it was not proving to be effective in clearing the infection.

20. His second round of treatment was in 2003 and was also through the Glasgow Royal Infirmary. That was a combination of Interferon and Ribavirin. This treatment lasted for twelve months but it was not successful, again it had failed to clear the infection.

21. Dad did not have any troubles accessing treatment.

22. I do not believe there were any other treatments that my Dad could have had at that time that he wasn't able to receive.

23. Dad's infection did not have any effect on his treatment for anything else as far as I am aware.

24. Mentally, the treatments my Dad received for the infection changed him into a different person. My Dad was always a family man and he loved us all so

much, but the treatment changed a lot about his personality. It caused severe depression for him, there would be whole days where he would just lock himself away in his room and not speak to anyone. My sister and I were living at home at the time and it was hard to see him isolating himself like that. His mental health was very bad during the treatment. He would also have quite bad mood swings, you just never knew what sort of mood he was going to be in when you saw him. It felt like he had changed into someone that we didn't even know.

25. Dad would have a lot of fatigue because of the infection, it took a lot out of him physically. You could tell that he would struggle to do things he normally wouldn't have a problem with, things like getting out the house or going to work. He lost a lot of weight during both treatments, whilst they were ongoing he went from being quite a big guy, six foot tall and broad, to being a beanpole. He lost so much weight he was basically just skin and bones. The treatments also caused night sweats for my Dad, my Mum would often have to get up in the middle of the night and change the bed sheets because they would be soaked through. The treatments also caused a lot of very bad itching for my Dad all over his skin. He would describe it as feeling as if there was something underneath his skin, it seemed to be constant and it never went away.

26. The infection took away a lot from my Dad, he basically didn't have a life. His relationship with both my Sister and myself was deteriorating because he just wasn't the person we knew anymore. He stopped going to visit his mum, he didn't want any contact with his brothers or sister either. He just cut himself off from everyone around him, he stayed in the house, in his room by himself and didn't want to see anybody. The only person he would really speak to would be my Mum, he pushed everyone else away.

27. My Dad was never really one for socialising, even before the troubles he had with his infection. My Dad's idea of a good night would be a night in the house with me, my Mum and my sister so I wouldn't say the infection changed his social life really.

28. When I was younger, my Dad's infection didn't really affect me. It was when his treatments started that things changed, I felt like I didn't know who he was anymore. His temper could be quite scary at times, I could never know what kind of mood he was going to be in when I saw him. When I was still living at home, there would be times where I would be coming home from work and be worrying about what version of him I would be seeing when I got home, it made me feel constantly on edge. There would be times where he would get into bad arguments with my Mum and that would make me feel quite emotional because she was only trying to look after him. I'm quite like my Dad in a way, we don't really talk about our emotions that much but that could lead to us having arguments ourselves. Once, after one of these fights we'd had, he kicked me out of the house in my pyjamas and my Mum came home from work to see me sitting round the side of the house in cold. I had to go and stay with my Auntie that night because of the mental state my Dad was in that day. There was only one time he was physical with me, I was in the house with him, my Mum and sister were both out, we got into an argument over something like the football and he started hitting me when I was in my bed. We used to watch the football together a lot but he never used to let things get that bad. Even when it was happening that night I knew that wasn't really my Dad, he wasn't like that before the infection.

29. We as a family never experienced any stigma because of Dad's infection, we just didn't tell anybody. There was a worry between us that someone might find out and things would change but nothing ever did.

30. Work wise my Dad was able to keep going through the infection until his second treatment in 2003. I think he may have had to take the odd day off before that but it wasn't something that happened often. He was only able to keep working for a short while at the beginning of the treatment in 2003 before he had to go on sick leave from work. I could not say how long he had to take off but I know it was maybe ten months. Physically and mentally he just could not continue to work, the treatment was too much for him. For

somebody like him, who was used to working twelve hour shifts six or seven days a week, to not being able to do anything was a huge change for him.

31. Having to stop working had quite a financial effect as well, there was just less money coming in. My Mum also had to go down to part-time at her job to help look after my Dad. It was very stressful time because there was still a mortgage to pay and there was only really the sick pay coming in. My Sister and I were both working and living at home at the time but to be honest we didn't really know a huge amount about the financial side of things, we just knew that they were struggling.

Section 6. Treatment, Care and Support

32. My Dad did not face any difficulties in accessing treatment, but in terms of care and support, he did not receive any care or support. After he was told that his second treatment had failed, my Mum asked if there was any kind of counselling he could get, but by the time they got back to her my Dad had already left the family home.

33. No counselling or psychological support was ever offered to my Dad before my Mum asked about it. I don't know if something like that would have helped him because he was such a private person.

Section 7. Financial Assistance

34. My Dad received £20,000 from the Skipton Fund sometime around the beginning of 2004. My Mum and Dad found out about the fund through the Haemophilia Society which they used to attend. To apply to the fund my Dad just had to fill out some forms. There were no difficulties in applying to the fund as far as I am aware.

Section 8. Other Issues

35. I have nothing else to bring to the Inquiry's attention.

Statement of Truth

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

Signed GRO-B

Dated Sep 6, 2020