Witness Name: GRO-B
Statement No.: WITN1975001
Exhibits: WITN1975002 –
WITN1975006
Dated: 12 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B My address and date of birth are known to the Inquiry.

Section 2. How Affected

2. I am writing this statement in memory of my mother, GRO-B: M who contracted Hepatitis C (HCV) from a blood transfusion in 1979 or 1980. She passed away in 2011.

3. Before my mum became ill, she was a very active person. When I was young we had horses, and she very much enjoyed looking after them and spending time outdoors. I was very close with my mother; our personalities were similar.

4. My mum had her gall bladder removed at Joyce Green Hospital in Dartford, Kent in 1979 or 1980. This hospital is now closed. She was given a blood transfusion during this operation. **(WITN1975002).**

5. I do not know whether anything was explained to mum before or after she received the blood transfusion about the risks of being exposed to infection. However I do not believe that she was told of any risks, back in those days they just gave you a transfusion if you needed it.

6. My mother did not find out that she had HCV until 20 years later. She found out after just a routine visit to the GP in 2000. She had been complaining of tiredness for a long time. She was always very lethargic; on some days she did not want to get out of bed at all.

7. I found out about her diagnosis a short time later. I remember it like it was yesterday. We were in the car one day and she told me that she had HCV. I thought that it was like HIV, and she said that it wasn't like HIV but that it could be sexually transmitted. She said "How the hell did I get Hepatitis C? I do not drink, I do not do drugs." She never had a man in her life since I was born, and she never drank a drop. The only thing that she could think of was the blood transfusion for her gall bladder operation.

8. I don't know what the GP told her about the infection or how to manage it. As far as I am aware she did not get any help or guidance. She was referred to a liver specialist, at GRO-B who did a liver biopsy and diagnosed her with grade 2 inflammation and stage 2 fibrosis **(WITN1975003).**

9. I do not think that she was advised to contact the Hepatitis C Trust or anything like that. She just carried on. I don't think that she knew what was involved and what the infection would do to her; no one knew at that time what the major consequences of HCV were. I don't think she had an understanding of what HCV meant for her, if she had she would have tried to seek some kind of help.

10. My mum did not mention that there was a risk that she could pass the infection to others, I think if she had been told about this risk she would have mentioned it to me.

11. I believe that information definitely should have been provided to her earlier. To be honest, she should have been diagnosed less than 20 years after the blood transfusion. If she had been diagnosed earlier maybe things could have been done about it and maybe her life would have been prolonged. By the time she was diagnosed, her liver had already started to flare up.

12. As I was not there when she was told I do not know exactly what was said but it felt as if it was all very casual, to find out after a routine blood test and to be told "oh you have hepatitis C", with no support, no advice and no information given.

13. Mum always suspected that it had been the blood transfusion that had infected her but she did not know for sure. She was not aware that there were other people who had been infected through blood transfusions; it had not been highlighted then. At that time there was nothing public about contaminated blood. I'm sure she would have mentioned her suspicions to the GP but I do not know what he said to her in response.

Section 3. Other Infections

14. I do not think that my mum received any infections other than Hepatitis C.

Section 4. Consent

15. I do not know whether my mum was treated or tested without her knowledge, consent, without being given adequate or full information or for the purposes of research.

Section 5. Impact

16. The effect that HCV had on my mum was primarily fatigue: not being able to leave her bed, not having the energy to get out of bed. This started before she was diagnosed, around 10 years after the gall bladder operation.

17. Sometimes she could not leave her bed because of the lethargy. Her heath spiralled because she could not get up and she could not exercise. She gained quite a bit of weight and she developed diabetes, I think this was caused by fatigue and lack of exercise. She was not burning off anything because she was not exercising and could not get out of bed. It was debilitating for her.

18. She would go back to the doctor time and time again because she was so tired, and they told her different stories every time she went. She was told that it was the menopause or that she was taking on too much, but they did not test her for HCV until 2000.

19. If she had not had the HCV her energy levels would have been higher. She got a dog and I suggested that she walk the dog for exercise, but even that was too much. The onset of diabetes was written on the wall. She was later told that she had heart disease, which I believe was also because of her fatigue. She was not getting up or moving around. She was also diagnosed with hypothyroidism and asthma.

20. She was always quite a sad person from what I remember. But I do not think that she really realised the effects of what it meant to have HCV. She was very private about it and did not speak to me about the emotional effects on her very much.

21. Not long after she was told about the HCV, her liver function deteriorated and she realised that this was what was causing the fatigue. Then it all made sense, all the symptoms that she had been suffering all this time. After being diagnosed in 2000 she was then diagnosed with Stage 2 fibrosis of the liver, and then with cirrhosis of the liver.

22. After that her health further deteriorated. She was fading away; she slept most of the time from 2000 to 2011. She was just always unwell, and lacked energy. I was working full time so I would see her once a week or every couple of weeks. I did not realise the implications or the seriousness of it at the time.

23. I don't know what treatment she was offered for the HCV. She had lots and lots of tablets, but I know that she had lots of other ailments; I don't know which tablets were for what. I know that by 2005 she was taking 225mg of Azathioprine, 6mg of Budesonide and 10mg of Pravastatin daily, and by 2008 she was taking 250mg of Azathioprine daily and 3mg on alternate days of Budesonide **(WITN1975004).**

24. On 23 February 2011 I received a phone call at work to say that my mum had fallen at home and had broken her hip. **(WITN1975005).** I got to the hospital straight away. She needed an operation but had gained lots of weight and as a result she could not be given a general anaesthetic. They gave her an epidural instead. She did not come back from that. She died on **GRO-B** 2011. **(WITN1975006).**

25. I do not know of any treatments which should have been made available to her. She should have been offered something if it would have cleared the HCV, but I think the disease might have been too advanced by the time she found out about it. If she had been diagnosed earlier they might have been able to give her some kind of treatment

26. I do not know whether her infected status impacted on her treatment for any other conditions.

27. Mum did not have a social life, as she slept all the time. She was basically bedridden with fatigue. In the first few years of the fatigue she got out and about a bit but then she could only go out in the car. In the end she would not go out, she would just stay in her bedroom.

28. Mum's chronic fatigue did impact our relationship. For about ten years after her gall bladder operation, she was fairly well. She still went out with the horses and spent time out and about with me. I must have been about 20 years old when she started to feel fatigued and stopped being able to participate in my life fully. I wasn't aware of the seriousness of this; to me it happened gradually and I was in my early 20s, living an independent life. However, I was aware that she wasn't well and couldn't do the things other mums could do.

29. In about 1995 or 1996, I took my mum and my daughter GRO-B to Disneyland Paris. Mum had never been away apart from on a coach to Austria, and I was earning good money at the time so I thought I would treat her to a holiday. GRO-B was 4 at the time. I had organised the holiday mainly for her enjoyment. I had booked one of the nicest hotels in the area and taken her on the Eurostar. But when we were there all mum wanted to do was sleep. She said "you go round the park, I'm going back to the hotel to sleep". We were only there for a few days, and she was in bed asleep for 75% of the trip. I think she only came out with us once during the whole trip.

30. A few years later I tried to encourage her to come to Florida with me but she said that she did not want to go, that she did not have the energy.

31. She would look after my daughter while I was at work. She did not have the energy to run around with her or anything like that, she would just sit down on a chair while GRO-B was in the house.

32. My Nan, my mum's mum, lived with my mum in the later years and helped take care of her. By then Mum could not really do things for herself, and my Nan and GRO-B were her main carers while I went to work. We would have to make her dinner, she would come down and then would go back to bed. After Nan died, Mum's brother moved in to look after her. Nan died first and then mum died two years later.

33. I have not been well at all since mum died. It has affected me very badly. I had a nervous breakdown after her death. I wanted to be with her and I did not feel that I could carry on without her. I started taking anti-depressants and at times considered suicide. I am still on medication now and still hurt as deeply now as I did right after she died in GRO-B I never got over her death, and to think that it could be the responsibility of infected blood is terrible, it was not even natural causes. She died at 60 and could have lived much longer.

34. The loss was terrible for everyone. My daughter GRO-B is also on antidepressants and has been since we lost my mum. Mum was a second mum to GRO-B when I was working, dropping her off and picking her up from school and giving her tea when she got home. Mum's death had a devastating effect on GRO-B but she kept it all in and then she rebelled and lashed out. Losing her great-grandmother (my nan) in 2009 had already seriously affected GRO-B and then losing my mum two years later was the final straw. She went seriously off the rails after Mum's death and took her anger out mainly on me. She wouldn't see a counsellor or speak to anyone about it. Now she will not even go to the grave because it brings everything up.

35. Mum hardly told anyone about the HCV. I think her mum and I knew about it but that's it. GRO-B did not know, and I don't think mum's brother knew either. I think she felt embarrassed. It is not something she wanted to tell people in case they thought that she had slept around or done drugs. I have only ever mentioned it to some close friends of mine. Mum did not ask me not to tell anyone but I knew that she did not want lots of people to know.

36. It was degrading and embarrassing for her to have HCV although it was through no fault of her own. No matter what you say, there is a stigma attached to it, I am surprised that she even told me. I have not ever had a negative reaction from friends, family or anyone else but I have supportive friends. I imagine it could have been a lot worse.

37. Before she became ill, my mum was a secretary for the Royal Bank of Scotland. She was one of the fastest typists I have ever known. But she had to give up work because of the fatigue.

38. I used to work for Ernst & Young as a PA to three senior partners. I started work there in 2008. I had always worked in busy high pressured jobs. When Mum died in 2011 I had a nervous breakdown and they gave me six months off work. I then went back to work until 2014. Eventually they let me go as I was struggling with depression and was not well enough to return.

39. After leaving Ernst & Young I worked at several PA and administrative jobs at various companies, but didn't stay at any of them for very long. My last job was working at M&S for a few hours per week as a Christmas temp. I am looking for a new job now and have a few interviews lined up but I worry that I won't be able to keep a job because of my depression.

40. Since Mum died I cannot seem to hold a job down. I am on universal credit but I am also I cannot take on a more permanent role, I can't commit to working long term because of my depression. The financial impact of this has been huge; I went from earning a good salary to having to working a few

hours a week, which has had a massive impact on my family and has meant that we are struggling to make ends meet.

Section 6. Treatment/Care/Support

41. I do not think my mum faced any particular difficulties obtaining treatment.

42. My mum was definitely not ever offered counselling. They just told her that she had HCV, they did not investigate how she had been infected and did not offer her any support at all as far as I am aware.

43. I have not been offered counselling in consequence of what happened to mum. I did see a counsellor for 6 sessions which was provided by Ernst & Young after my mum's death. However, it was so painful to talk about what had happened that I was discouraged from continuing to seek help after these sessions finished.

44. If I were offered therapy or counselling again I would like to try it because I am still unwell and really want my depression to go away.

Section 7. Financial Assistance

45. I found out through my solicitors representing me at the Inquiry that there was financial assistance available to people who were infected by contaminated blood. I had never heard anything about the trusts and funds before a few months ago. I have looked into it; I am now waiting for my mum's medical records so that I can make the application.

46. From what I know about the application process so far, I think that the financial assistance could be made easier for people to access. The forms look complex and there are lots of medical questions which I would find

difficult to answer without mum's records or without a doctor to help me. I have heard that the application process takes a long time.

Section 8. Other Issues

47. I have my suspicions that information was withheld from my mum and from others. I think that when my mum was diagnosed with HCV it should have been noted that she could have been given infected blood. She was never told that, not by the doctors. But mum said it as soon as she had been diagnosed, she knew in her head that there was no other way that she could have got it.

48. When I first heard about the Inquiry on the news there was an interview with a lady who had been infected with HCV. She was explaining the exact symptoms that my mum had; the lethargy and having no energy. It just all rang true. Her story was exactly the same as my mum's. I had not heard of anyone else being infected by contaminated blood. When I found out the scale of it and how many people it had affected I was shocked.

49. I had a blood transfusion in the early 1990s and in the last few years I have started to feel very fatigued. I went to see my GP and she said that it might be the menopause, just like mum had been told. I was so worried that I had been infected too that I demanded a test; they confirmed that I do not have it. Mum having HCV has always eaten away at me. Once I find out the truth about what happened I hope that I can move on and put this whole thing to bed.

50. I think that the Inquiry team and the Chair must be diplomatic. They must reach out to families directly rather than reaching out to officials. From what I have seen so far I do trust this Inquiry to do this. I like the way that everyone, my solicitors and the Inquiry team, have been so supportive.

51. I do not hold the NHS responsible because their hands were tied; it was the decision makers who at the time allowed that blood to be given to patients.

Without a shadow of a doubt I want someone to take responsibility and to accept their errors. They must be accountable for their actions, they have killed their own people and they should not be allowed to get away with it.

52. I want those responsible to stand up and be counted and for the Inquiry to make sure that nothing like this ever, ever happens again. It is too late for some. I wonder how many people who had an operation in the 1970s or 80s are sitting at home now fatigued, unable to get out of bed with no knowledge that they have HCV. How many people must have passed away without knowing that they had HCV? This scandal affects so many people, it is big and it will get bigger.

Statement of Truth

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

Signature: ..... GRO-B

Dated ....12.02.2019..................