Witness Name: Mr Rodger Lowe
Statement No.: WITN2700001
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WRITTEN STATEMENT OF MR ROGER LOWE
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is Rodger Keith Lowe and my date of birth is GRO-C 1973. My address is known to the Inquiry.

2. To introduce myself, my name is Rodger Keith Lowe. I live with my wife Natalie of almost 14 years, my stepson Joshua aged 18 years and our son GRO-C aged 13 years. My daughter Olivia aged 19 years is an active and regular part of my immediate family. We have two puppies, Ivy a Border terrier and Willow an English springer spaniel. I am employed full time as a railway worker and part time as a door supervisor.

Section 2: How Affected

3. The person infected was my mum, Barbara Lowe. She wasn't just my mum; she was a wife to my father Keith Lowe, mother to my two sisters Rachel and GRO-B Nan to GRO-C Jack, Olivia, GRO-C, GRO-C and GRO-C and finally great-nan to

GRO-C. She was sister to Glynis, Brian, Linda, Anne, Ayleen and Keith and an aunty and great-aunty.

4. My mum Barbara was my rock, always putting us as her children first. She never let me down. Mum always tried her best at everything, whether that was being our mum, a Nan or out working. She had a great sense of humour and tried to always put a smile on our faces. At Christmas she always tried her best to get everything we asked for, despite not always being able to work due to her ill health.

5. Mum had a good relationship with lots of people in our small village, I felt that they looked up to her and on her passing people commented how the local area would be different without her. One fond memory I have and would like to share is mum always waiting up for me when I had been out with friends on nights out for me to bring her a Chinese in.

6. My mum was infected by a blood transfusion given during an operation on 13 February 1988 for mitral valve replacement. She had developed a heart condition that required swift replacement of the mitral valve. The operation was scheduled to be performed late 1986 or early 1987 at Northern General Hospital in Sheffield. This first operation was cancelled due to an infected tooth that needed removing or treating to prevent further physical ill health. Northern General thought it prudent to remove all of her teeth. My mum had an infection in a tooth at the time and they thought it was necessary to remove all of her teeth so that this would eliminate the risk of infection during the surgery for the mitral valve. The removal of the teeth ended up having a seriously detrimental impact on her mental health and self-esteem. Following the removal of her teeth, while she was waiting on her mitral valve replacement operation, my mum suffered a serious stroke that affected elements of her long term and short term memory, such as not being able to recall my birth date. I remember this day well as it was my sister GRO-B's 11th birthday and mum's own sister was in labour with her second daughter. Due to this it was agreed that someone in

the family would always attend appointments with her so as to ensure the appointment details were written down. Someone in the family recorded the stroke was attributed to a blockage somewhere in her heart. My mum passed away on 13 October 2014, her death certificate recorded that she died from 1a. Cardiogenic shock; 1b. Calcific aortic stenosis; 1c. Chronic lymphatic leukaemia. My sister Rachel would not sign the death certificate initially because the hepatitis C and the kidney disease were not listed on the death certificate. Rachel was told that the body would not be released for burial if she did not sign it, so she had to.

7. Mum did not suffer bleeding disorder.

8. In preparation for the mitral valve operation my mum was told in the presence of my Father that an element of the operation was the requirement for a blood transfusion. Mum was told that the blood would be of American origin. My father recalled my mum asking if she could have her own blood taken out and re-infused. They denied the fact it would be possible to re-infuse my mum with her own blood and on that basis my mum accepted that she would need the blood transfusion. Mum and Dad had the conversation about it and how it would be good to have a real American's blood.

9. To the best of my knowledge, I don't think that any prior information or discussions were held with regards to the risk of infection from a blood transfusion. Mum and dad were told the transfusion was an essential element of the procedure.

10. Mum was later found to have been infected with hepatitis C (HCV).

11. Some years on from the blood transfusion my mum's deteriorating physical heath was investigated because none of her current diagnosable physical health conditions could be responsible for her symptoms which included shortness of breath, dizziness, lethargy, joint pain, and nausea. From my

recollection, I think mum attended her doctor's surgery first and was then referred to the Royal Hallamshire Hospital in Sheffield where her consultant Doctor Gleeson conducted investigations; it was from these investigations that my mum was informed in October 2003 that she had been infected with hepatitis C.

12. My sister Rachel went with my mum to the Royal Hallamshire to get the results from the tests that were conducted. Rachel reported that she and my mum sat outside in the waiting room and waited for the most part of the day to see Dr Gleeson and he explained in a very blunt and unsympathetic manner that my mum had hepatitis C and that she had become infected from the blood transfusion in 1988. I understand that they stated this because they said there was no other way she could have become infected; it was due to the lack of piercings, tattoo's, sexual promiscuity and as she was not, nor had she ever been an intravenous drug user (IVDU).

13. I am unsure as to whether any information was provided at that consultation with regards to the adequacy of the information to help them to understand and manage the HCV and including risks associated with it. I recall there being a lot of shock, anger and confusion at time. I do recall that in 2008 my mum asked my wife Natalie who was a student nurse at the time to find out all the information that she could about the hepatitis C. Natalie this and provided it to my mum. Mum kept hold of this over the years and it is my belief that this was the only source of information to her about the infection.

14. From around 2000 I recall that mum had started to become more seriously unwell with explained symptoms. She was regularly visiting her GP and the hospital for regular blood tests. It is my belief that these blood test results would have revealed something that required further investigation into her liver function. I think that my mum should have been monitored closely from the point at which she received the blood transfusion. If there was a risk attached to receiving blood then she should have been monitored so as to proactively

deal with that. I understand that there is evidence that from 1975 contaminated blood products were infused into patients with haemophilia and it seems that from the early 1980's it was found that blood transfusions from blood sourced from America were given to patients following childbirth, operations and trauma. Work should have been done to identify those who had been given a transfusion and where this was so, they should have been tested to see whether or not they were infected with the virus.

15. The information was not delivered to my mum in a timely or sensitive manner.

16. I was never told that there could be a chance that others could contract the virus from my mum. I am also sure that this information was not provided to my father, the fact that this virus could be contracted through sexual contact. I have had to have difficult conversations with my dad since.

Section 3: Other infections

17. Mum was infected with hepatitis C only.

Section 4: Consent

18. I do not believe that my mum was treated or tested:

without her knowledge;

without her consent; but

I do believe that she was treated without being given adequate or full information as she was never informed of the risk of receiving a blood transfusion, so she was not informed of the full facts to enable her to make a fully informed decision.

I do not believe that mum was treated or tested for the purposes of research.

Section 5: Impact

19. The impact of the infection on mum and our family was huge.

20. The mental and physical effects of being infected were that suffered a lot of joint pain which prevented from being as mobile as she once was. She relied on my dad, me and my brother-in-law a lot, as a result. She experienced a lot of nausea; she was on a lot of medication so it is difficult to be sure whether the nausea was caused by the hepatitis C. Mum was always physically and mentally tired but unable disconnect from her mind. She sometimes had to have night sedation because she could not sleep. She bruised very easily, I expect this might have been because of the warfarin but I do not know. I also recall that she was jaundiced. She developed an acute risk of infections as her own immune system was so compromised. It ended up that she was sick all of the time. Towards the end of her life she lost a lot of weight. My mum also lost a lot of her self-esteem. I think that she became depressed because she was not physically able to do the things she used to any more. She kept saying that she felt terrible and was ready to go.

21. My mum was diagnosed with Mitral Stenosis in 1988, Osteopenia in 2008, Chronic Kidney Disease Stage III in 2009, Aortic Stenosis in 2014, and Chronic Lymphatic Leukaemia in 2011. I am unsure whether the conditions other than the mitral stenosis resulted from the infection but they could have done given that my mum received the infected blood, in 1988.

22. Mum's symptoms continued and deteriorated over time. I recall that from at least 2003, perhaps before she was always sick. Over time she became really, really poorly all of the time. She passed away on 13 October 2014.

23. I understand that my mum was given interferon for the hepatitis C and that this contributed to her heightened symptoms.

24. I understand that when mum was diagnosed with the hepatitis C, she started the treatment for the infection pretty quickly but by this stage she had already waited 15 years.

25. I am not aware of other treatments that could have been made available to my mum.

26. Mum developed chronic lymphatic leukaemia and it my belief that this came from the treatment that she received for the hepatitis C. I remember that she had no energy whatsoever and was in so much pain, so bad that she could not do anything that she normally did. She would try to suffer through it because she wanted to have as normal a life as possible and she would welcome people around for a visit but you could see she was totally exhausted and would have to lie down afterwards.

27. Sometime following her diagnosis, mum was taken to hospital and placed on a bay with other females who also had hepatitis C as a result of IV drug misuse. This caused her great emotional upset because she felt stigmatised by her infected status.

28. The impact of this on mum's private life was really significant. I think that the physical side of their relationship was affected because of the hepatitis C; mum stopped sleeping with my dad GRO-C GRO-C Mum and dad were an old fashioned couple, when her condition deteriorated she needed more help from my dad but because he had not fulfilled that role before it was not easy for him and so this caused friction in their relationship. I think it greatly affected their marriage. In terms of the impact on my mum's family life, I think that there was a lot of frustration in the family that she had become so sick as a result of what was done to her. Mum still came to the family functions and visited her friends because she had a lot of support, but she could not have done it without that

support and I think that she no longer enjoyed the fun that was there any more. Her life became different.

29. The impact of the hepatitis C on me emotionally was more anger and sadness. I am angry and sad that my mum has missed out on so much: the marriage of her granddaughter; the birth of her great-grandson and on her grandchildren growing up. She lived for them. She spent so much time with them as it made her happy. She is no longer there for me. I always spoke to my mum about things that were going on in my life. I can no longer to this. I had suffered a relationship breakdown with my daughter. My mum's contact with her was minimal; mum would have loved to see that contact re-established which I managed to do last year. I know that this would have made mum happy but she is not around to see it.

30. Throughout mum's life she always spoke about the fact that when she died she wanted to donate her body to scientific research. When it came to putting the plan in place properly, she found out that because she was hepatitis C positive that she would not be accepted. This made mum very upset and angry. She wanted people to learn from what she had been through. She also did not want to burden us her children with sorting out her funeral arrangements. We all remember this and it makes us very sad that her dying wish could not be carried out.

31. The family is devastated about mum not being around anymore. It is felt by everyone. Her sisters, brothers, children, grand and great grandchildren. My dad has changed completely. He is more of a hermit now. He will not leave the house or socialise with anyone. I have tried to get him out of the office a number of times but he will not leave.

32. Mum could not continue to work as she was not physically able to. She had to reduce her hours first and then stop work completely because she could not keep up with the duties.

Section 6: Treatment/ Care/ Support

33. I do not believe that she faced difficulties or obstacles in obtaining treatment, or care as a result of being infected with HCV but I do not know for sure. I do think that mum should have received support and I do not think that this was ever given. I know that she struggled with the infection in her mind. She really needed education. This was never given and I think that this shows a real lack of support and care towards mum. I have found that there was the possibility that she could have received financial support yet somehow she was never told. She did ask if there was help available and she was told no.

34. I don't think psychological support was offered to Mum. It definitely was not offered to me.

Section 7: Financial Assistance

35. No financial support was offered to mum and in fact when she was trying to find financial help she asked her consultant whether it was possible and was rudely dismissed by him and told to "get on with it". So, she did not receive any payments.

36. We only found out about financial assistance and the availability of Trusts when researching the Infected Blood Inquiry further. We are now trying to see if there is assistance available for my dad but to date we have not received anything.

Section 8: Other Issues

37. I do not have any evidence which would be relevant to the Inquiry's investigation.

38. I do not have any documents which might be relevant to the Inquiry's Terms of Reference. We have recently requested the records but these have not arrived

yet and so I would like to have the opportunity to make a supplementary statement to the Inquiry should that be necessary following the receipt of those records.

39. I would like the Inquiry to find out the truth; to find out what went on, why my mum received blood that was infected with hepatitis C and why she only found out that she had it 15 years later. I want to know why mum was never told about there being financial support that could have been given to her to make her life that little bit easier. I want my mum's voice to be heard, she always wanted to be compensated for her suffering, she always wanted to know why she was given the infection and knew she would not get the answers in her lifetime and so she wanted us, her children to do it for her so that her pain would not have been in vain. She does not want this to happen to other people in the future.

40. I think that information was withheld from my mum; particularly in relation to her infection. She was never told what carrying the infection meant, how it might impact her life or the seriousness of it. She was never given advice about financial support when this was readily available to others.

41. I have concerns about the accuracy of the death certificate as it does not include information on her hepatitis C at all despite this being raised at the time that it was supposed to be signed. We do not have her medical records so I cannot say whether they are accurate or complete.

Statement of Truth

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

Signed: GRO-C

Full Name: Rodger Lowe.

Date: 20 · 2 · 2019