

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN3323001

Exhibits: WITN3323002

Dated: 18th March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

Section 1. Introduction

1. My name is **GRO-B**. My date of birth is **GRO-B** and my address is known to the Inquiry.
2. I live in **GRO-B** with my husband and three children **GRO-B**. **GRO-B**. My eldest daughter **GRO-B** is married and lives nearby, and I have had a son, **GRO-B**, who died of septicaemia at the age of 17 months in 2001. My family have always been the most important aspect of my life and continue to be so.
3. My qualifications are Registered General Nurse (RGN), Registered Midwife (RM), Specialist Community Public Health Nurse (SCPHN) School Nursing BSc (Hons), Post graduate Certificate in Teaching Higher Education (PGCTHE) and I am a Teaching Fellow for the Higher Teaching Academy. I also hold qualifications in the field of sexual health.

Section 2. How Affected

4. My Mum, GRO-B: M whom I was extremely close to, became infected with Human Immunodeficiency Virus (HIV) through an infected blood transfusion on the GRO-B, 1996. This was administered at Whiston Hospital, Prescott, Merseyside and the blood had been transported from the Royal Liverpool Hospital.

5. Mum was in hospital at the time, having been recently diagnosed with Multiple Myeloma and receiving treatment for it. She required a blood transfusion due to her low haemoglobin level. I remember, at the time, my mum discussing the risks and benefits of chemotherapy with her consultant Dr. John Tappin, and she asked the question, "How long do I have to live if I do have chemotherapy?" Dr Tappin replied, M, if you are having chemotherapy, we are looking at 3-5 years." This was taken by us to be reliable information and was something we could tangibly work towards, based on my Mum's blood chemistry results and Dr Tappin's knowledge and expertise.

6. This conversation took place in September 1996, around the time Mum received the infected blood transfusion, yet she died only 8 months later on the GRO-B GRO-B 1997.

7. I can remember Mum complaining of flu type symptoms in the September 1996, post transfusion, saying she had aching legs and arms, had a headache and was feeling really run down. I remember having this conversation with Mum as I had just told her I was pregnant again and she was really pleased for me, as I had delivered a stillborn little girl GRO-B months previously, and she didn't want me to "get any bugs" from her "flu" that could affect my unborn child. On reflection, her flu type symptoms must have been a symptom of becoming infected with HIV.

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8. Mum never knew she had become HIV positive, as my sister and I were informed of this five days after her funeral. My sister and I then had to inform my father that his wife had become infected with HIV.
9. I am aware, as a professional, that chemotherapy affects your CD4 count, which is indicative of a person's reduced immunity, and that this was and still remains the treatment of choice to treat multiple myeloma and prolong my Mum's life at the time. However, due to Mum becoming infected with HIV, her CD4 count would have undoubtedly decreased further, making her more susceptible to infection. I understand that HIV-infected patients have increased risks of symptomatic multiple myeloma and earlier death.
10. It was never explained to my Mum or family at any time that there could be a risk of HIV from receiving the blood transfusion, or any other blood borne infection.
11. This risk was dramatically increased in that staff had not adequately screened the person who was donating the blood, as if they had, the person would have been categorised as 'high risk'. I would also add, as a health professional acting within my own clinical practice, I was trained to believe blood was safe to be transfused following the process of blood screening and this included my Mum and all the patients and babies I looked after.
12. After my Mum's funeral, my Dad went to visit the North East for a few days, where he and Mum spent time together before they married, to feel close to her again. It was during this time, five days after Mum's funeral, that it was disclosed to my sister and I that Mum had received blood infected with HIV. This devastating news was given to us by Mum's GP, Dr. GRO-B and Consultant Haematologist Dr. V. Martlew.
13. We were told it had been discovered that two other patients had become HIV positive through receiving blood transfusions from the same donor

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that my Mum had. We were told that the lab still had samples of my Mum's blood after her death (I am unsure why this would be so, or if this was indeed true) and this blood was had been tested, and it was confirmed that Mum was HIV positive. It was at this point, in my Dad's home that he had shared with my Mum, that Dr Martlew acknowledged that "the person who was giving the blood at Liverpool had not been screened properly by staff and would have been high risk." No further information was given to us. Neither doctor provided any information about the effect of the virus on my Mum's illness and death.

14. I felt the diagnosis should have been communicated in a more professional way, in a clinical setting, rather than in my parents' home. I felt vulnerable in that I felt compromised receiving the diagnosis in such a way that I could not offer professional challenge.
15. My mum should have been diagnosed earlier so she could have received more responsive care and had the opportunity to make informed choices about her treatment. I cannot believe Mum was diagnosed after her death, thus allowing increased risk for transmission to my Dad and myself who cared for Mum.
16. I remember feeling angry, as I felt this was complete professional negligence in providing adequate safe care. I rang the laboratory at the hospital where I worked the following day after being told Mum had been HIV positive and asked if it was possible to contract HIV from a blood transfusion, even after all the learning from the 70s and 80s scandal into patients receiving infected blood products. The laboratory staff member explained that the screening process was "robust now", although this was clearly not the case for my Mum. He discussed the "window period" where there is a period of a month where a person can be infected with HIV but it would not be detected by a test. Yet, I remember thinking that the person was "high risk" who had donated their blood, so their blood should never have been used.

17. My sister and I then realised that there was a real risk my Dad could have contracted HIV from my Mum. We had to wait until Dad returned from his few days away, revisiting the places he and Mum both went to, to ask my Dad if he had had sex with my Mum after she had received the blood transfusion. This is not a question you would ever imagine a daughter having to ask her father. We both had to tell Dad that Mum, his wife, had contracted HIV from the blood transfusion.
18. Later that day, we had to share the traumatic news with my brother. This was such a hard conversation to have, especially at the time when all our grief was so raw, having just buried Mum.
19. We also explored the idea of Dad and ourselves being tested for HIV. This was at the time when if you were tested for HIV, this could still have a detrimental effect on many aspects of your life, such as obtaining life insurance, and even being tested for HIV at all made you subject to stigma. Dad died five years later with his HIV status unknown.

Section 3. Other Infections

20. As far as I am aware my mum was infected with HIV only.
21. I am aware that my Mum could well have been infected with other blood borne infections, however, we have never been informed of such.

Section 4. Consent

22. I strongly believe my Mum would never, ever have consented to receiving the blood transfusion on GRO-B 1996 had she known the full risks involved, including becoming infected with HIV and reducing her life expectancy somewhat dramatically, especially when such a high risk donor had not been adequately screened.

23. I am also aware that a research paper was published by Dr. V. Martlew and my Mum is described in this article as the 'Third infected recipient'. I have found this unbearable reading, as I read my Mum described as this. The article is cited at; Post-transfusion HIV infection despite donor screening: a report of three cases. *Journal of Hospital Infection* (2000) 44: 93-97 V.J.Martlew, P.Carey, C.Y.William Tong, J.V.Parry, F.J.Belda, K.L.Barlow, P.Chu and Q.Syed. **(WITN3323002)**. Confidentiality is most important to me, and I wanted to protect my Mum's good name and reputation, as I know she would have experienced great distress if others had become aware of her HIV status. The fact that this research has been published has affected me deeply, and I found this harrowing to deal with. I am trying to find the words to describe how I still feel about it and I would still describe my feelings as ones of horror, wanting to protect my Mum who I feel has been treated as a statistic in this paper to perhaps further one's career.

Section 5. Impact

24. I believe my Mum did have physical symptoms of HIV during the time she was alive. She complained of aches in her arms and legs, headaches and feeling run down. We thought she had the flu.
25. My Mum was never aware that she had HIV, but she was concerned about the flu-like symptoms that she had, and in particular was worried about potentially getting me sick, as I was pregnant at the time she was ill.
26. My mum was never able to have treatment for her HIV as she never knew that she had it. Perhaps if she had received treatment, she could have lived longer.
27. Mum had planned to write to us all (myself, my Dad, brother and sister) about what we had meant to her, our lives growing up, her memories.

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She wanted to do this so we could feel close to her when she was no longer with us and read her letter, but due to her rapidly decreasing health, she was unable to do so. Mum desperately wanted to meet her grandson, my son [GRO-B], who was born 7 weeks after Mum's death, especially as I had given birth to a stillborn daughter in [GRO-B] 1996. I strongly believe that if she had not been infected with HIV, my Mum would have lived to see and hold my son [GRO-B] and my second son, [GRO-B], who was born in [GRO-B] 1999, less than two years after the conversation when Dr Tappin confirmed Mum would live for between three to five years.

28. I would care for my Mum on many occasions, assisting my Dad to meet all my Mum's needs. This was while I was pregnant and working as a midwife. This was a difficult time in my life in terms of caring for my mum whilst working full time and pregnant. Emotionally, I felt exhausted, but I wanted my mum to be cared for as I would want to be cared for.
29. I remember on one occasion Mum asking me to read a post-it note she had been given by a member of staff after discharge from the hospital for the attention of the district nurse. It stated, "This patient has MRSA". Mum asked me what this was. I was horrified that this information was given in such a way and without any explanation to my Mum. Mum was really worried and I explained to my Mum what this was and tried to reassure her that this was probably due to a hospital acquired infection alongside her reduced immunity.
30. Mum never knew she had received infected blood with HIV, and I know she would have been horrified had she done so. My Mum was not kept adequately informed by doctors and this is not an acceptable level of care. My father and I should have also been informed as Mum's carers, and especially due to my pregnancy, which was advanced by this time (30 weeks), and it is widely evidenced how a pregnant woman's immunity

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is reduced in pregnancy. There seemed to be a lack of compassion where professional behaviour and attitude was not as I would expect.

31. I was watching the national news the week after my Mum's funeral, when the newsreader read the headlines of three people in the North of England becoming HIV positive after receiving infected blood. I was 34 weeks pregnant at the time and remember falling to my knees, rocking and breaking down in uncontrollable sobs. I remained like this for some time, feeling I could hardly breathe through the utter helplessness and grief I was feeling. I feel I have not been able to grieve properly for my Mum's death due to this trauma I experienced.
32. I would breast feed my new born son, crying in the knowledge that Mum would have been horrified had she known her HIV status. Mum was a Catholic, a GRO-B and a pillar of the community. This was at a time when HIV was still stigmatised as an illness drug users and gay men suffered from and this is the reason Mum would have been horrified that she had this condition. Many people within the church community shared this belief and the Catholic teaching even today does not recognise homosexuality and sees it as a sin. It does not bear thinking about what the Catholic community would have thought about my Mum had they known she was HIV positive. My Mum would have been distraught.
33. I had a deep fear of contracting HIV due to caring for my Mum prior to her death even though I knew the chance of this was extremely slim. I did not share this fear with anyone. My son GRO-B was a sickly baby and it was always a worry to me that he may have contracted HIV through utero transmission from me. I did not share this fear with anyone and these thoughts stayed with me for many years.
34. My father was concerned that he could have contracted HIV from my mother, but he decided never to be tested for HIV as he thought that

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having an HIV test in his records would cause him to be stigmatised by medical professionals. Dad felt he did not want to know and perhaps this was due to fear, but he also did not want having a record of an HIV test in his medical records to affect his insurance information as it would have back then.

35. My second son **GRO-B**, born in **GRO-B** 1999, never met his Granny and he died on **GRO-B** 2001. I always worried he may have been HIV positive too, through utero transmission from me, having such a detrimental effect on his immunity. Again, I never shared this fear with anyone. We also had to endure a second funeral for **GRO-B** nine months after his first one following the discovery that the hospital where I was employed had retained 21 parts of him without our knowledge or consent. This was after the Redfern Inquiry into the Alder Hey scandal.
36. It took me a further 15 years before I would be tested for HIV and discover my status once and for all. I had convinced myself the results would be positive and was afraid to be tested because of that. I worked full time whilst waiting for the results and I was terrified. Can you imagine living with that fear for all those years?
37. It has actually not been until I have written this statement, that I have realised just how much Mum's HIV has affected me personally and professionally all these years, as well as the effects on my health. I now realise I have suffered physical and emotional symptoms of post-traumatic stress disorder and continue to do so. I am aware of the evidence that psychological trauma can lead to physical symptoms of ill health and I remember feeling helpless and emotionally out of control when informed Mum had become infected with HIV.
38. I was in a state of anxiety, shock, bewilderment, numbness, feeling such a depth of sadness that would not leave me and a feeling of being out of control, overwhelmed and tearful. I remember visiting my GP at this time

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and broke down at the enormity of it all. I was losing my hair and my GP explained it was my body reacting to the shock and stress of discovering Mum's HIV status. I would be awake in the night, breast feeding my son with tears streaming down my face, feeling such isolation and sorrow.

39. I suffer with insomnia at times, anxiety and depression for which I have been prescribed anti-depressants on different occasions and have been diagnosed with supra-ventricular tachycardia (SVT) which is triggered by stress, auto immune conditions for which I need on-going medical treatment and irritable bowel syndrome (IBS) which can be most debilitating at times. Whilst writing this statement over the last three days, my IBS has flared up causing stomach cramps, diarrhoea, nausea and weight loss.
40. I can recall many situations in my professional career where my Mum's HIV status was at the forefront of my mind. I was studying a sexual health course at university and a HIV Specialist Nurse came in to discuss his role. He went on to share how there were three people infected with HIV from a blood transfusion back in the 'late 90's' and I was most aware he was talking about my Mum. My heart was pounding as my anxiety soared, my head was aching, my legs and arms felt heavy and I was trembling whilst trying to maintain my composure. I returned to work after this, feeling exhausted but having to maintain my professionalism.
41. This would happen again and again in different situations throughout my professional and personal life where I would need to remain outwardly calm when I was emotionally wrecked. I would regularly teach young people aged 13 – 14 years old sex and relationships education as part of their personal, social and health education (PSHE) and would advise on safe sex, including how HIV can be transmitted and the fact there is no cure. My colleagues and manager were unaware of how emotionally drained I would feel after these teaching sessions. I became the GRO-B GRO-B for the Department of Health with the delivery of the

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National PSHE/Continuing Professional Development (CPD) Programme, teaching and advising public health leads, teachers and community nurses of sexual health matters, including HIV.

42. After my Mum's death, I continued to practice as a midwife on a neonatal unit where it was common practice to administer blood transfusions to sick babies. The thoughts that constantly went through my mind at the time were of the babies becoming infected with HIV, and their parents not been told of the risks by the doctors.
43. I never told anyone of my constant fear and I did not have a supportive manager during this time. My manager had previously told me I couldn't have a career and children, and when I needed a new uniform due to my increasing pregnancy size, she told me I had had too many maternity leaves, by which I took to her meaning I had had too many children. I would have felt completely disloyal towards my Mum if I told anyone of her HIV status, especially to such an unsupportive manager, even though it felt like my head was going to explode.
44. Eventually, I felt I had no other option but to give up my midwifery career. I realised I could not go on administering blood transfusions to mothers and neonates due to my constant emotional turmoil and fear that they may become HIV positive. This was in April 2001.
45. I look back on my career as a midwife and describe this role as the best role I have had, and would say most definitely that I would still be practising today if it wasn't for the way Mum's HIV status affected me. I excelled in midwifery practice and introduced innovative ways of working to improve outcomes for mothers and their babies. I still have many thank you cards I received from mothers and their families as my time as a midwife. The decision to give up my midwifery career impacted on me and my family greatly, in that my take home pay at that time was £1500

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per month and this reduced to £880 when I stopped working as a midwife. We became in debt as our outgoings remained the same in terms of mortgage, bills, etc but I could not emotionally remain in the job that I loved.

46. In terms of my family, if my Mum had not been infected I could have had longer to spend with my Mum, my children would have had more time with their Granny, and [GRO-B] and [GRO-B] would have known Mum who would have loved them so much. I have only recently explained to all my surviving children that their Granny became HIV positive after receiving infected blood, and this has increased my feelings of anxiety as I want them to have lovely memories and thoughts about their Granny, not have them replaced by her HIV status. I also felt the need to protect them from this, as I am only too aware of the stigma that is still associated with such a diagnosis.
47. My Dad was deeply affected by the expedited loss of his wife through becoming infected with HIV. Dad died not knowing his own HIV status, and we spoke of his rational fear that he could be HIV positive but he chose not to be tested.
48. My brother, [GRO-B] has written; "My mother was diagnosed with HIV when I was planning to get married. The adverse effect it had on her health meant that she was unable to attend my wedding in early 1997, a source of regret ever since. Because my mother was unable to attend, my wife and I decided to get married with no family or friends present rather than exclude her specifically. I still feel sad and somewhat bitter that the mismanagement of my mother's health by the National Health Service badly impacted on what should have been a happy family occasion."

Section 6. Treatment/Care/Support

49. Mum was unaware she was infected with HIV. I would argue that had she known, she would most definitely have declined chemotherapy through informed consent as this would have had a detrimental effect on her immunity and expedite her death.
50. Counselling or psychological support has never been made available to me as a consequence of what has happened and I have lived with this trauma for over 22 years. It was never offered to my Dad, brother or sister.

Section 7. Financial Assistance

51. My Dad did receive compensation from what I think was the Macfarlane Trust, and I remember him saying it would help pay for Mum's funeral costs and his own in time.
52. I have not received any financial assistance from any Trust or Fund.
53. I was aware there was a Trust set up to provide compensation for those infected/affected (for my Dad as Mum's next of kin) but I was never informed that I could receive compensation nor was I contacted.

Section 8. Other Issues

54. My Dad received some funds that he described as "from the government". There was a precondition that he had to sign a disclaimer that he would not seek compensation and was advised he could never make this public knowledge. This was never a legal case, as he had been advised he could not sue the government (I remember Dad telling me Jack Straw, MP had stipulated this).

Statement of Truth

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

Signed

GRO-B

Dated 18th March, 2020