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Witness Name: GRO-B

Statement No: WITN3957001

Exhibits: 0

Dated: January 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B, will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B 1971 and I live at GRO-B
2. My mother, GRO-B M (born on GRO-B 1944), was infected with the Human Immunodeficiency Virus (HIV) from contaminated blood products and/or transfusions. She died on GRO-B 2012 at the age of 68, as a result of Acquired Immunodeficiency Syndrome (AIDS).
3. This witness statement has been prepared without the benefit of access to my mother's full medical records.

Section 2. How Affected

4. My mother was unwell for as long as I can remember. She had Chrohns disease and developed iron deficiency anaemia. She had ulcers on the bowel

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and was in constant agony. Ultimately they started to remove parts of her bowel. My mother was treated with iron infusions and B12 injections. She was also treated with blood products and/or blood transfusions. My mother had countless operations, treatments and procedures over the years. My mother's health started to deteriorate further from the mid to late 1990s onwards and in the latter years of her life the medical profession were unable to get to the bottom of why she had become so very unwell.

5. My mother had a low immune system and no-one could work out why. She was not tested for HIV until the day before she died. Two junior doctors suspected AIDS because, when admitted to hospital, she did not respond as they had expected to the treatment provided. My mother never knew that she had HIV/AIDS. There was nothing the doctors could do for her and she died the next day (on GRO-B 2012).
6. My mother was HIV positive for at least 10 years before her death, probably much longer. My father, my brother and I saw an HIV specialist two days after her death and we were tested for HIV. The HIV specialist explained that my mother had probably been HIV positive for years and years. The Coroner tested material taken at a biopsy my mother had in 2002 for evidence of HIV at that time and it provided a positive result.

Section 3. Other Infections

7. I do not believe my mother was infected with anything other than HIV.

Section 4. Consent

8. I do not believe my mother was tested or treated without her knowledge or consent. She was only tested for HIV the day before she died.

Section 5. Impact of the Infection

9. My mother (Mum) struggled throughout her life with terrible health issues. Mum was a proud, strong and stoic person. She was a battler. When my two brothers and I were young we were shielded from the worry of what was wrong with Mum and I am unable to provide a detailed medical history as a result. I recall Mum being in hospital for weeks on end in or around 1980. Our grandmother came to look after us and we visited Mum in hospital on many occasions. In 1990 I went to visit Mum's sister in Australia. Mum did not come to the airport to see me off and I later found out that Mum was having a major operation to remove part of her bowel and I had been 'shipped off' so I would not see how poorly she was.
10. Mum had several minor operations and biopsies in several hospitals local to us through the NHS and privately. She had several treatments and procedures to include endoscopies. Mum was consistently poorly from the mid to late 1990s onwards. After the major operation she had in 1990, she had two more major operations.
11. Mum never gave up. Mum and I job shared. We worked as **GRO-B** **GRO-B** in local government from around 2001/2002. The job share arrangement enabled me to work whilst Mum looked after my young children. She would turn up for work no matter how tired or sick she felt. She would even come to work having had no sleep the night before. She would do a day's work and then go home to sleep.
12. Before becoming very unwell, Mum led a full and active life. She was very sociable. She was a member of a **GRO-B** group. She was an amazing granny. She played badminton and tennis with dad and she practised her Catholic faith. She was an all round good person.
13. The health issues Mum suffered with in the latter part of her life were directly attributable to HIV/AIDS. She suffered with countless colds and tummy bugs

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through having a compromised immune system. Mum had pneumonia twice and she was very poorly with it. Mum had shingles several times. She then had post herpetic neuralgia and wore morphine patches on her back. Mum suffered with persistent outbreaks of thrush in her mouth. I remember a holiday we had planned being completely ruined by one such outbreak. Mum had a rotten time. We had to find a doctor for her in Spain.

14. Mum began to lose weight. I noticed that she wasn't eating well and I suspected that she was anorexic. She would push her food around her plate and even hide her food in her bag. I used to make snacks and little treats to try to tempt her. Mum also had a sore red rash on her cheeks and lower face she could not get rid of. Mum was always at the GP surgery but she could not get to the bottom of what was wrong. I think she was at the surgery on a weekly basis for years and years.

15. Mum was under a haematologist for two years. Mum's blood cell count was low and she was thought to have Sjogren's syndrome/a form of blood cancer. As serious as that was, Mum was actually glad to think that she finally knew what was wrong. She said to me "I have something to tell you but don't worry because I am glad I know. It can be treated. I have Sjogren's syndrome." She was so hopeful that she would start to get better again. On the very day Mum was due to start her chemotherapy, they ran a further blood test and she was told by her haematologist that she didn't have it. Mum was mortified. Dad said she was inconsolable. She was sobbing because she thought that they had finally got to the bottom of the problem and they hadn't.

16. Mum had to give up work early because of her ill health. She would often go to Australia to visit my brother and he was shocked at how poorly she looked when he last saw her. I had written to him to warn him (and to provide him with a list of 'dos' and 'don'ts' in relation to Mum's apparent unwillingness to eat) but there was no preparing him for how thin she looked. I thought that Mum had an eating disorder as did her GP. I was worried and I used to nag her about her eating habits and that created tension between us. Through

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frustration, I even shouted at her on her birthday. Around the same time she collapsed at a family do. I came across her diary after her death. I had no idea at the time just how much pain she was in. She was unable to get well and it was out of her control. My dad and I would take two hour shifts at home watching her and trying to get her to eat something. I remember how horrible it was. I put so much pressure on her and I feel so guilty now. She was physically unable to eat and it wasn't her fault.

17. Two weeks before Mum died, I insisted on going with Mum to a GP emergency appointment as she was dizzy upon standing and so thin and unwell. I said to that GP 'I am watching my Mum die here. She is dying in front of me (sorry Mum) and nobody will help her get better'. The doctor said he was monitoring Mum and that he had referred her for psychiatric help (she was on a waiting list). He suggested that we were wasting his time and that we should not have taken an emergency appointment. We had a row with me insisting Mum get the help she needed straight away. He then said he would do his best. She had just one appointment with a psychiatrist a short time later. She had waited for the psychiatrist for six months.

18. My parents lived with me in an annex/granny flat. Mum was admitted to hospital after Dad called me in to them a short time after my own birthday GRO-B and only a couple of weeks after the emergency appointment with the GP. Dad was worried about Mum. She was acting very strangely, sitting in her coat with her bag in her lap and saying weird things. At the hospital they said she should have been admitted much sooner. She had had a lung infection for some time (causing the dizziness when trying to stand) and was severely dehydrated and malnourished. She was skin and bone. She had had a bleed to the brain and she had a clot on the lungs and a serious infection, we were later informed was attributable to AIDS. We were told that there was nothing they could do for her and, at that point, my older brother immediately flew home from Australia. We all took it in turns to sit with Mum so that she was never on her own. We lost her on a GRO-B evening with my older brother at her side, some 10 hours after Dad and I were

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informed of the HIV/AIDS diagnosis. Mum never found out what was wrong with her.

19. We were in a world of our own when Mum died in the manner that she did.

We were in a daze and I was so worried about my dad. We (my father, my younger brother and me) had to be tested for HIV, wait for the results and then go through the same process again three months later. I went with dad to all the meetings with the Coroner. The Coroner would not agree to an Inquest. My Mum had operation after operation, test after test, injection after injection (iron infusions and blood products) yet the Coroner said they were **probably** not the source of infection, instead suggesting sexual transmission as the source.

20. That suggestion has created untold distress for my dad and we do not accept it. I have rarely seen my dad cry but he did when he told my mother's family members what the Coroner had said. My dad is a respectable, proud and private man. We lived in a village, in a small community and there is a great deal of stigma associated with HIV/AIDS from ignorant people out there still. Dad asked me not to tell anyone outside of our family. He did not want people to treat us differently or think of Mum differently. We told people that Mum had died because of a blood clot. They already knew/believed that she had an eating disorder. The subject very quickly became taboo. Dad and I only ever spoke to each other about it at home and in whispers. It was very hard for me to process. I needed the support of my friends at that very difficult time and without being able to confide in them I had no support. I felt like I was lying to my friends. Mum had a very close friend, **GRO-B** who worried about my Mum and her health. We never even told **GRO-B** the truth and I feel guilty about that to this day.

21. Mum wasn't promiscuous. She wasn't a drug dealer. Mum wasn't working in a high risk environment. Mum and Dad had a monogamous marriage. My mum was a devout Catholic, and was married to my dad for nearly 50 years. Mum never strayed. My Mum was very close to her sisters and cousins. She was very, very close to one of her sisters. We have asked them to be honest on the subject of whether Mum could or would have had an affair and they

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have unanimously said '*No way, never in a million years would she ever have had an affair.*' Our whole family rallied around Dad and re-assured him that there was no way that she would have done that.

22. We were in a terrible state of shock when my Mum died and had to get on with the task of arranging a funeral. We buried Mum's body rather than cremating it in case we could find out more and in order to prove that my Mum was an innocent victim. Mum was a good honest woman with Catholic principles and she suffered poor health for years and years. She tried so hard to get better. With the exception of my brother (the only person equal to her), Mum was the strongest person I have ever known. She just got on with it. My dad later obtained a number of Mum's medical notes and records but struggled to get the records from the private hospitals where my Mum had treatment. I am aware that a lot of the medical notes and records were missing from the ones he had, but I recall him showing me a note made by our GP dismissing HIV as a potential diagnosis because Mum was not promiscuous or a drug user etc. Dad has since been diagnosed with Alzheimers and will now unfairly go to his own grave with that seed of doubt implanted by the Coroner in relation to Mum's fidelity.

23. Even though Mum never complained, my children only remember their grandma as being ill.

Section 6. Treatment/care/support

24. My Mum never even knew she was infected with HIV and had no treatment for it. She was never offered any counselling or support.

25. My family and I were never offered counselling or support but we did meet with a HIV specialist the Monday after she passed away to be tested.

Section 7. Financial Assistance

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26. My family never received any financial assistance from any of the trusts and funds.

Anonymity

27. I wish to remain anonymous and would like my Statement redacted before published by the Inquiry. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-B

Dated

25.02.2020