Witness Name:

~ RNON~

GRO-B

	Statement No: WITN5299001						
	Exhibits: Nil						
		Dated: 20 May 2021					
	INFECTED BLOOD INQUIRY						
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	WRITTEN	STATEMENT OF		GRO-B			
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				equest under Rule 9	of the Inquiry		
Rules	s 2006 dated	15 February 2020.					
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١,	GRO-B	will say	as ione	ows: -			
Saati	on 1 Introd	ation					
Secu	on 1. Introd	uction					
1	My name is	GRO-B		My date of birth is	GPO B		
•	1963 and n	ny address is	***************	GRO-B	GRO-B		
G	RO-B I am 58	3. I have been marr	ied to r	GRO-B ny husband GRO-B	since August		
1985. We will have been married for 36 years this year. We have two children GRO-B who is 33 and GRO-B who is 30 and married. We							
	have two grandchildren who are four and two years old.						
	nave two g	randomidien who d	io ioui	and two yours old.			
2.	I had a 40 v	vear career with the	NHS	before retiring on	GRO-B		
				L			
2021. I worked for 40 years, initially in primary care and community health until becoming deputy director at GRO-B in							
	Glasgow.	becoming deputy	00101		j"'		
	Jiasgow.						

- 3. I intend to speak about my mother, GRO-B: M who was infected with Hepatitis C (HCV) following three blood transfusions received between 1968 and 1978. I do not know from which of these transfusions she contracted HCV. In particular, I intend to discuss how the virus has affected and continues to affect her health in the forty years which have followed and moreover, the impact this has had on our family and our lives together.
- 4. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I can confirm that my family and I do wish to seek anonymity.
- The Inquiry Investigator has explained to me 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
- 6. I wish to acknowledge that as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Affected

7. I was born in GRO-B in 1963. I am the eldest of three. My brother

GRO-B is in the middle aged 54 and my sister GRO-B

GRO-B was born in 1968. She is 52. We moved to GRO-B

when I was four years old. We have lived here all our lives.

8. Growing up, we were a very close-knit family. My parents were always vibrant and social characters with a strong social infrastructure. When we were younger, we spent a lot of time at the golf club where both my parents were captains. My mum was always fit and active with a 'cando' attitude. She set up her own businesses and was particularly

forward thinking for her generation. She was also glamorous and would often get glammed up for dances. She always looked fantastic. Her work took her to cities such as Denmark and London where she would return with fashionable clothes for her self and us.

9.	As far as I am aware she had	I no underlying health is	ssues. In 1968, my			
	sister GRO-B was born at the	GRO-B	which has since			
	closed. To the best of my knowledge, we were all born there.					

- 10. During GRO-B birth Mum haemorrhaged quite badly, as a result of which she was given her first blood transfusion. I am told that my dad was informed that he had a daughter but that he had lost his wife. My mum remembers then being told by my Uncle GRO-B 'it's not your time

 M GRO-B had passed away years go.
- 11. My mother recovered. She was then given a second transfusion in 1974 due to heavy bleeding from her uterus. Between 1976 and 1978, she again experienced heavy bleeding, this time following a hysterectomy.
- 12. As a result, she was given a third transfusion. I was 13 or 14 at the time. I therefore believe that my mother was infected from one of the transfusions received in the 10-year window between 1968 and 1978, although I do not know which one was the contaminating operation/transfusion.
- 13. In the late seventies, when I was in my second or third year of high school, she started to become unwell. She was tired a lot and would take to bed for long periods of time. She was always in and out of the doctors' surgery with various ailments. Yet, no one could identify what was wrong with her.
- 14. My mother's health complaints persisted over the years. She would have periods of illness. As the medical profession could never identify the root cause of her problems, for a long time, I feel she was

dismissed as a hypochondriac. Her parents died under this impression, as did my father's mum which is awful to reflect upon given that we now know that she was suffering from HCV. She was told to just pull herself together and get on with it.

- 15. Subsequently, doctors thought that she had ME. Then, in around 2017, a new rheumatologist at Hairmyres Hospital saw my mother for her arthritis. This was due to ongoing issues with her joints which would intermittently necessitate the use of walking sticks. The rheumatologist was convinced that the arthritis was not her main problem and that there was another underlying issue.
- 16. She was then seen by a haematologist who then referred her to the Glasgow Royal Infirmary Hospital for a lumbar puncture and or bone marrow biopsy.
- 17. As a result of the aforementioned procedures she was told that she had had Hepatitis C at some point in the past, which she most likely contracted from one of the transfusions she received in the seventies. Whilst she continued to have antibodies, the virus was no longer active and as such, she did not require treatment. That said it would appear that the virus took its toll on her body.
- 18. My mother does not have tattoos nor has she received medical treatment abroad. She only has her ears pierced. Besides the occasional glass of wine, she very rarely consumes alcohol.

Section 3. Other Infections

19. When my mother was referred to the haematologist for blood tests, she was told that she would also be tested for HCV and HIV. Fortunately, the latter was negative.

Section 4. Consent

20. My mother consented to the blood tests that were undertaken during this time.

Section 5. Impact

- 21. My mother suffered from Hepatitis C undetected for forty years. She has just turned 81 and has spent half of her life in ill health. When she was diagnosed, the haematologist told her that a review of her medical records would most probably indicate that many of her health problems over the years were attributable to the virus. He told my mum that the virus had burnt itself through her system leaving a trail of damage.
- 22. When my mother received her diagnosis, I think she was initially relieved that there was finally an explanation. Then I think she felt bitter that she spent forty years of her life in ill health, bouncing from one illness to the next, punctuated with pockets of wellness. In the past she might have experienced six good days for every bad day. Now, the pendulum has swung; she probably has 10 bad days for every one day in reasonable health.
- 23. As previously mentioned, by the point at which my mother was diagnosed, the virus was no longer active. As such, she did not require treatment. However, I don't think she would be well enough to receive treatment in any case. She is presently recovering from a recent heart attack, not withstanding her other illnesses.
- 24. When I was growing up, I can remember that she would experience urine infections, chest infections, fatigue, nausea, dizziness and other aches and pains for which she was prescribed medications. I can recollect that one medication caused her to hallucinate. When she

recovered from a bout of ill health, she would live life to the absolute full again.

- 25. My mother now suffers from a whole catalogue of illnesses which I believe may have been triggered by the HCV which remained untreated in her body for several decades. Between the early to the mid 1980's, she was diagnosed with type 2 diabetes. This has caused her to loose the majority of her sight; she is now registered as blind.
- 26. She has always been slim and healthy and as such I do not believe there are dietary causes for this illness. At one point she was given an insulin pump to provide her with regular insulin throughout the day and night but this had to be discontinued due to the deterioration of her sight.
- 27. Sometime in the early 1980's she was diagnosed with ME. In retrospect, I think this might have been a misdiagnosis for the HCV. When she was diagnosed with HCV, the haematologist also told her that the virus had damaged her bone marrow resulting in her being diagnosed with Myelodysplaisa which means her bone marrow was unable to produce enough white or red blood cells, as a result of which she now requires regular blood transfusions.
- 28. She is now in a pre-leukaemia state due to the hepatitis. She has heart disease, osteoarthritis and skin conditions which manifest in lesions for which she receives light treatment. This is reasonably effective. She suffered a major heart attack six years ago and had stents inserted. Then further heart attacks in October 2020 and April 2021.
- 29. Growing up, our family life was undoubtedly impacted by my mother's ill health. She was often not always up to taking on household responsibilities. The house would often be a mess and neighbours would have to cook our dinner. My dad did what he could but he was working two jobs as my mum didn't work for periods of time. He worked

as a lecturer full time and part time in a dental surgery. He only retired when he was 87. He tells me that he cannot understand why people want to retire.

- 30. My mother stopped working full time before my son GRO-B was born in 1988. She worked as a dental health educator for a GRO-B GRO-B which involved driving up and down the country.

 However, she wasn't well enough to sustain this job. She has not worked since.
- 31. As the eldest child, household responsibilities often fell on my shoulders. I would be asked to tidy the house. I also looked after my younger siblings. I would drop them at school, go to registration and then bunk off. My six-year report card detailed 117 absences! This wasn't because I disliked school but merely because I wanted some time to myself. I would wander off to read or watch TV. A lot of responsibilities were placed on the shoulders of a teenage girl and that was my coping strategy.
- 32. On one occasion, the school called my parents to tell them that I was required to attend detention. My father told them that they needed to change the date because I had to look after my brother and sister as my mum was in hospital. I achieved my standard grades and my Highers. However, I was bright and I could probably have done better if I hadn't felt compelled to balance my education with household and caring responsibilities.
- 33. I remember periods of time where I felt overwhelmed by the responsibilities at home. I would often leave my home and take myself off to my grandparent's house for a bit of respite. They would also help out by cleaning our house and making dinner. My dad's mum lived into her nineties so she was also available to provide support.
- 34. My mum helped me with childcare for both my children. When my kids were older, my mum helped out at the golf club as a secretary on a part

time basis. However, there was always an unreliability in relation to this as we would often expect a phone call from my dad to say that mum was not well and that someone else would have to pick up the kids from school.

- 35. Very often, this fell on my grandmother. However, she was in her late 70's early 80's at this point. Fortunately she was very fit and up until the day she went into hospital, she took on a lot of responsibilities that my mother was unable to undertake due to her ill health.
- 36. My father is 88. He has always been very active. He is a keen gardener and has always done all the cooking. About six or seven weeks ago, he became unwell and had a pacemaker fitted. His resting heart rate was 140 but would drop to 20. I think this is caused by the ordinary wear and tear of old age.
- 37. This has been exacerbated by the lockdown, which has caused him to put on some weight. They are both tired and worn out. As a young lady mum loved to shop, sadly now doing a food shop is too exhausting for my mum who certainly feels a certain pressure to remain in good health in order to ease the burden on him. Mum is registered blind and Dad deaf, together they function okay but when separated it is difficult. This has been more evident during their recent hospital admissions.
- 38. My mother has not experienced any stigma as a result of her diagnosis with HCV. I don't think she associates the virus with dubious sources such as drug addiction but then times have changed. Both my parents will say that the care and treatment they have received from the NHS has been exceptional.
- 39. As her immunity is so compromised, the last time she was in hospital over a year ago, she was given 'reverse barrier nursing' People with leukaemia will have this sort of treatment. Now she will have to go into a single room in hospital. However, this is to protect the patient from

outside infection as opposed to any perceived risk the patient poses to others.

- 40. Whilst Mum did not experience any "labels" regarding her health, I did. About 25 to 30 years ago, I was at the GP surgery getting one of my children vaccinated. I overheard the receptionist answering a call from my mother. She was a good friend of hers who has since passed away. I overheard her muttering, 'What's wrong with her now?'. I'm sure my mum was labelled a persistent attender or something along those lines.
- 41. I think my mother is bitter that she has had forty years of her life stolen from her, which affected her capacity to live her life as fully and richly as she would have hoped. This caused her to become depressed and tearful at various points throughout her life. If her infection had been diagnosed earlier, she might have been subjected to stigma, but then she might have also received treatment which could have prevented the host of health problems from which she has suffered since.
- 42. My father, on the other hand, is quite accepting. I think he just thinks that the hand you are dealt is the hand you are dealt and there is no point dwelling on the past.
- 43. My mother's ill health has affected me more in my adult life. It has been difficult juggling childcare responsibilities with trying to keep an eye out for her. It has often fallen onto my sister GRO-B because she only worked part time whereas I always worked full time. My brother GRO-B lives nearby my parents, as such, he is always ready and willing to help out when necessary. I think he has found it difficult watching their health decline. But then it's impossible to pinpoint what is caused by the HCV and what is the ordinary course of old age.
- 44. My parents always loved holidays and going for cruises. However, I don't think my mum would be able to do it now. The last time they went mum became unwell and they had to make an insurance claim for her treatment, this experience frightened my dad. Recently they wanted to

- go on a 5-day cruise around Scotland this year but realised they would have to pay £1500 for travel insurance.
- 45. This is the first time I have discussed the impact of my mother's health on myself and our family.

Section 6. Treatment/Care/Support

- 46. As mentioned previously, I am sure that my parents would say they have received exceptional treatment from the NHS. Nevertheless, I am aware that my mother feels bitter that despite persistent visits to the GP and hospital with a myriad of health complaints, her illness was not diagnosed sooner. In my view she was made to feel like a hypochondriac, other people thought that as well.
- 47. Indeed, she has had numerous blood tests over the years yet the virus was not identified until 2017. Years ago, she was prescribed a painkiller for her arthritis. Doctors realised that they couldn't give it to her because her liver function tests were raised. Her liver function tests remained elevated in more recent years when she suffered a heart attack. Even with the raise in her LFT's no one considered doing a test for HCV or any further investigations.
- 48. I have noticed a change in the way medical professionals treat my mum since her diagnosis. Her GPs are much more responsive now. I think they experience a degree of guilt that her illness went undiagnosed for so long. As a result, they are now comparatively very accommodating to her needs. I think my mum probably doubted herself at many points in her life.
- 49.I don't think my dad has ever been tested for HCV. Nevertheless, he has been a regular blood donor throughout the course of his life.

Therefore, I feel confident that my mother did not transmit the virus to him.

- 50. Neither myself nor my siblings have ever been tested for HCV. However, my mother received the transfusions after we were born so she could not have transmitted the virus to us in vitro. At one point I became concerned when I recollected how growing up there were always bloody hankies lying around because she was always bleeding from somewhere. However, we all seem to be fine.
- 51. At some point after her diagnosis, doctors gave her a leaflet for the Hep C Trust. That was a few years ago. I don't think she attempted to get in touch with them. Then she was very unwell following another heart attack. I decided to look into seeking support as I knew her and my father could benefit from additional household aid. She now receives an attendance allowance.
- 52. Neither my mother nor my father have been offered any psychological support or counselling as a result of her diagnosis with HCV. I think by the time she was diagnosed, she was so unwell with other ailments, I don't think this would have even been considered.

Section 7. Financial Assistance

- 53. I recently supported my mother in her application to SIBSS. I printed off the forms and my mum signed them. We then sent the forms to the consultant haematologists to be completed. These were sent about four weeks ago.
- 54. In all fairness, I don't think the money would make that much difference to my mum and dad's current lifestyle, as they are financially comfortable, that said it would help with their future care.
- 55. At the moment they are happy and they have a nice home. They used to go on cruises, but they can't do this anymore. If her application to

- SIBSS is accepted I feel she would enjoy sharing some of the money with her grandchildren.
- 56.I am not sure if the success of her application depends on proving receipt of transfusion in the 1960's, as we couldn't get any records going back to 1968. We did however receive a DVD, which contained a vast amount of her medical history and information, which covered the 1970's.
- 57. From that I did find her transfusion notes I've got evidence that she received transfusions and that her haematologist told her that she had Hepatitis C at some point. This is marked clearly on her records.

Section 8. Other Issues

- 58.I think it is scandalous that the government allowed contaminated blood to enter the country. I would like to find out what happened. I would like to know why the decision was made to import blood from overseas. What information was this decision based on?
- 59. Having worked in the NHS for years, I understand that there will always be human error. What is important is that they are reported in a transparent way. Nevertheless, I am interested to know what state of knowledge informed the decisions that were made around the administration of blood and blood products during this time.
- 60. I would like to see the timelines including when the government became aware of the risks associated with blood and what actions were taken. Why weren't they screening the blood when they knew there to be risks involved? In some ways my mum was lucky. Others have been devastated by this to an even larger extent.
- 61. I don't blame the NHS as they merely administered a product they were given. However, I am keen to know how and why they received

this product. Usually, if there is a shortfall in blood, the government would put a call out and people will rally around. My dad gave blood throughout his working life and encouraged us to do the same. He had all the badges. Mum couldn't because she was slightly anaemic.

- 62. How did we allow such a deficit in blood supplies to transpire? When I worked at the Hospital in the early 80's if we were short, everyone would have donated and before you know it, we would have had thousands of pints.
- 63. I am no Shylock; I do not seek revenge, nor am I intent on seeing anyone go to prison. I just want to find out what happened. What's important for me is that lessons are learned. How do we make sure that this never happens again?
- 64. My mother turned 81 on the GRO-B 2021. Whilst I question whether she is well enough to provide evidence, she wants to make a statement. I know that it is very important for her that her voice is heard.

Statement of Truth

l believe t	hat the facts stated in this witne	ss statement are true
Signed	GRO-B	
Dated	20 May 2021	