Witness Name **GRO-B** Statement No: WITN3016001 Exhibits: 0 Dated: July 2019

## INFECTED BLOOD INQUIRY

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	FIRST WRITTEN STATEMENT O			GRO-B	
1,	GRO-B	will say as follows:-			
Sec	tion 1. Introductio	<u>n</u>			
	1. My name is	GRO-B	of	GRO-B	
	GRO-B	My date of birth is	GRC	D-B I currently wo	ork full time as
	а	GRO-B		I have an older b	rother and an
	older sister. 1 cu	irrently live alone. I h	ave an	ere-syear old son who	lives with my
	mother. He is a	GRO	)-В	ļ	

mother. He is a

- 2. I make this statement in relation to my late father, Mr **GRO-B** He was born on **GRO-B** 1 was GRO-B when my father passed away.
- 3. My late father was infected with Hepatitis C and HIV as a result of being treated with Factor VIII concentrate in order to manage his haemophilia.
- 4. This witness statement has been prepared without the benefit of access to my late father's full medical records. If and in so far as I have been provided with

limited records the relevant entries are set out in the medical chronology at the end of this statement.

#### Section 2. How infected

- 5. My late father suffered from severe Haemophilia A. I understand that he received Factor VIII Concentrate in the late 1970s and early into the 1980s. My parents were never told about the risks associated with these products. It was our understanding that my late father needed these products in order to survive.
- 6. My late father attended the Haemophilia Adult centre at the Royal Victoria Hospital (RVH) in Belfast under the care of Consultant Haematologist, Dr Butler, neé Mayne. He eventually went onto home treatment and my mother administered the injections for him.
- 7. My late father was infected with HIV and Hepatitis C as a result of being treated with contaminated Factor VIII concentrate. I only found out that my late father had been infected in approximately **GRO-B**
- 8. My parents had kept it a secret from me up until that point and I can only assume they did so to protect me.

# Section 3. Other Infections

9. When my mother first tried to obtain my late father's medical records she was informed that they had been destroyed. After several attempts, my mother did manage to obtain a copy and we were very surprised to learn that my late father had suffered with medical conditions and we had not been made aware. The medical records showed that my late father had been diagnosed with Viral Meningitis. We were never told about this and it was a condition that could have put the entire family at risk. There was a total lack of communication from the hospital and my family should have been told about

any medical diagnosis. I really do think that my late father contracted Meningitis as result of his infections.

#### Section 4. Consent

- 10. My parents were not told of any risks associated in receiving Factor VIII concentrate and even after my late father's diagnosis, it was not mentioned that the cause of infection was the contaminated blood products.
- 11. I recall that we were on a family holiday abroad and my mother read an article in a Spanish newspaper which headlined that Factor VIII blood products were contaminated. My mother brought that article home to the UK and when my parents questioned the hospital about it my late father was told to stop scaremongering people. My parents had discovered for themselves that the blood was contaminated and brought it to the hospital's attention, but nothing was done about it. In 1986, my late father received a letter from RVH informing him that he had been infected with HIV and the hospital had carried out the test in 1984. No one in my family was aware that any tests had taken place. The letter went on to say that the Factor VIII blood products had been contaminated. This letter was wholly matter of fact and there was no sense of severity or urgency.
- 12.1 understand that my parents received another letter which was much later and I think it must have been in the early 1990s. This letter informed my late father that he had also been infected with Hepatitis C. Once again my family were not aware that he had been tested for Hepatitis. As far as I am aware I do not believe that he ever received any form of treatment.
- 13. I most certainly do not believe that any form of adequate information had been provided to my late father. He could have been told about his infections so much sooner. It is clearly evident that there was a two year gap before he was informed of the HIV diagnosis. I feel that my later father was treated so badly and that he was treated like an animal.

14.1 remember reading about our entire family being tested in my late father's medical notes. I do recall that I had some tests and the hospital said they were checking my platelets, so I didn't really think about it. I didn't at that time know anything about his condition so I wouldn't have really thought anything about it. It was another thing the hospital wanted and we trusted our lives and care to them.

#### Section 5. Impact of the Infection

- 15.1 was thirteen when I found out that my late father really wasn't well. I was told by my mum in our home. I will never forget that moment. We were in a supermarket and he was pushing the trolley and he started shaking. I noticed the colours in his face changed drastically. He collapsed, his face went to one side and the security guard came to help us. I was with my big sister who was holding me back as I felt like I had stopped breathing. I was having a panic attack. When the ambulance arrived, my mother told the paramedic what was wrong with him and the ambulance took him off to hospital.
- 16.My mother told me that when my late father first found out about his HIV, he experienced a nervous breakdown.
- 17. In or around 1995, my late father was admitted into hospital with a collapsed lung. At that time he almost died and my mother warned us to expect the worst. We were all at the hospital and my mother was trying her best to hold everything together. One of my aunts also came to support us. There was an array of emptiness surrounding us. I remember seeing my late father lying unconscious in a bed with an oxygen mask around his mouth and tubes inserted into him. It truly was awful as he looked so helpless, but thankfully, he survived.
- 18. In 1996 my late father was given approval to go on a family holiday. We went camping in France for two weeks and it was the best holiday I ever had. Unfortunately my late father became really unwell and I recall that he had to receive day treatment at the nearest hospital for a couple of consecutive days.

- 19. In the mid 1990s, my late father had a metal plate inserted in his knee. After that the only medication I recall that he took was AZT, anxiety medication and steroids. However I do recall that his drawer was full of various tablets. Prior to taking medication, my late father was a calm and composed family man but the medication changed his personality completely. All of a sudden he became extremely volatile as the pain was unbearable for him. He always felt sore. He was a brilliant father, but there were times when I did not recognise him. My fun, loving and wonderful father turned into someone else and I didn't know why.
- 20. My late father's health was always on my mind when I was a teenager. I became pregnant at the age of seventeen. Meanwhile, my late father was very sick and my mother's health also deteriorated. She was bed bound with depression for a month. My siblings tried their best to keep the house going whilst also caring for my parents. My son was born on **GRO-B** 1999 and my late father was too ill to visit him at the hospital. He paid for me to be in a private room and in the night he would call me and make me laugh.
- 21. When I returned home from hospital with my new born son, I saw my late father and I knew he was seriously ill. He had lost so much weight and his eyes looked constantly bloodshot. I overheard him say to my aunt that he was so tired and that broke my heart. In January 2000 he felt even sicker and the doctor's knew he was dying. He was still at home and my mum said that he had never seen Paris before. Knowing that his lifespan was short, she booked time off work and arranged a last minute holiday to Paris. I have photographs of that trip and my late father looked truly awful.
- 22. On the Tuesday before his death, he started having issues with his mobility. He came halfway down the stairs crying from the pain because his stomach feit so sore. My mum was at work so I phoned her and said he felt very ill. The Ward Sister came to our home. He was admitted into hospital and Dr Orla McNulty found a tumour the size of a football in his stomach and told us that he had developed AIDS related cancer. Dr McNulty tried various medicines, but he passed away a few days later. I held one of his hands while my mum

held the other. I said to him, "Dad, we are going to be okay, so it is okay for you to go to the afterlife."

- 23. The death certificate listed HIV and Hepatitis C as the causes of his death.
- 24. I feel like I spent my childhood at the hospital, although I always assumed his hospital visits were for his haemophilia. I accepted things as they were because I didn't know any better. If I had a cold, I was told to wear a mask and I was not allowed to touch my late father's bathroom items. His toothbrush was isolated and kept in a separate case. I didn't question it because it was normal for us however looking back, I realise just how abnormal it was.
- 25. After my later father's incident at the supermarket my mum explained to me exactly what was wrong with him and my first thoughts were how could he possibly have HIV? Even in the eyes of a thirteen year old girl, HIV was a virus that affected homosexuals or drug addicts and my late father was neither. As my mum was explained it to me, I could not breathe and I suffered a panic attack.
- 26. After finding out about his infections, I would not leave my house, other than for school. My moods changed and I became very mature very quickly. I would not allow anyone to touch me, I became withdrawn and isolated. I had a one off seizure and at the age of fourteen, I was on anti-depressants. I was a complete mess and I could not bear the thought of losing my father. I was really close with him and the thought of anything happening to him was devastating.
- 27. When my later father passed away, I was so angry at him because I could not believe he had left me. It was selfish because I know it was not his fault that he was sick but I adored him. My whole life has been turned upside down by his death. At the age of 23 I was diagnosed with clinical depression and I have since developed obsessive compulsive disorder and anxiety.

- 28. At the moment my depression is under control however at times it can get really bad. I am really working hard on better management of my emotions.
- 29. My parents told us not to tell anyone about my late father's condition. There was such a stigma attached to HIV. I now understand that they were trying to protect me. In my first year of secondary school, I confided in a friend in confidence but she broke my trust and she told all my classmates. I was subsequently bullied for two and a half years. During that time, I had to eat my lunch alone and I had no friends. I was mentally tortured and endured being called dirty. Nobody wanted to sit next to me and even in class I had to sit on my own. I closed myself off completely and my mother noticed a massive change in me. I remember that my mum sat me down and asked me what was wrong. When I told her she complained to the school but the teachers were useless and did nothing to help me. Thankfully in my fourth year I met a good friend and things turned around for a while. I began to enjoy school again although the stigma never went away. I felt like the students and teachers remained ignorant.
- 30.1 was only a child when I found out about my later father and I really lost my way. I couldn't deal with everything and I started hanging out with boys and picked up habits like underage smoking and drinking. I was horrible to friends and acted out in a negative manner and I was no longer interested in school. I only managed to pass three of my GCSE's and failed the other five. I was a complete mess and I hated my life. I had wanted to be a nurse and if my father hadn't died and was still here today maybe I would be but I know that my life would be completely different.
- 31.My older sister tried to pull our family together. Between the three of us, she had the least of a childhood as she adopted the mother role **GRO-B**

GRO-Bmy mother had been so strong and brave.She was amazing as she managed to cope with a sick husband and three<br/>young children.GRO-BGRO-BMum buried her<br/>head in the sand whilst my sister, at the young age of 21, tried to sort out our<br/>debts and maintained the house. My sister also became pregnant. She took

on so many responsibilities, none of which she had asked for and none of which she would have had to if our father hadn't died. All three of us took on part time jobs to help raise our household income. We tried to earn as much money as we could because we were so desperate.

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- 32. My late father had initially owned a **GRO-B** shop which he sold. In 1995, he joined the Civil Service as a Clerical Officer, however shortly after he retired on medical grounds. He did not take that well and he had to rely on state benefits.
- 33. In the late 1990s my mum decided she needed to think of a plan to bring in more money but she had no qualifications and couldn't find a job easily. I remember that my mum went back to University and also worked part time as a secretary in a hospital. There was a period of time within that when mum

**GRO-B** 

**GRO-B** Gradually over the years she worked her way up and she was the Manager of Orthopaedics. She only retired last year.

## Section 6. Treatment/care/support

- 34. No counselling or psychological support was ever made available to my late father. The only support we were offered was to go to a place called the **GRO-B** Centre. This was designated for those living with AIDS and my late father made use of this facility. They used to hold events and he also embraced the friendships of others around him that were living with AIDS. The only real help they gave him there was protective condoms and massages. There was no proper counselling involved. The Centre sent us a representative once, coincidentally it was a previous priest of my school, who spoke with my late father. He asked how we were all doing but he never came back again.
- 35. My own counselling and therapy has been ongoing for years since the panic attack I suffered in the supermarket car park. My mum brought me to the GP who referred me for counselling.

## Section 7: Financial Assistance

- 36. In the early 1990s, my late father received a cheque for £70,000 and he used that to purchase the family home and I think he paid £40,000.
- 37. After my late father passed away, my mum received a lump sum of £20,000 from the MacFarlane Trust and for approximately one year she received monthly payments of £200. We received no assistance towards his funeral costs and my uncle paid for this.

#### Section 8. Other Issues

- 38. I really want to see justice for my late father and I want the people responsible to stand up and own up to their mistakes. I want them to admit that they murdered people in order to save money. They murdered my father and somebody should be held accountable. Most importantly I want to ensure that this never happens again as I wouldn't wish this on anyone. My mother was widowed and she has never been able to move on. My parents were best friends and they were made for each other. My heart breaks for my mum. She lost her best friend, her soul mate, her lover and the one person who knew her inside out. They stole the enjoyment of them growing old together.
- 39.1 feel my life may have been very different had my father been here today. My son would have his grandad and my later father would have been able to help my son understand more about suffering as a haemophiliac. He would have been an incredible role model to him. My late father was the person 1 could talk to about anything in life and had I grown up with him by my side. I know for sure that I would have made better life choices and decisions. He would have sent me back to re-sit my GCSE's and I would probably have studied to be a nurse. When he died a big part of me died too and I know that we would have been a different family.

# **Anonymity**

40.1 wish to remain anonymous.

41.1 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.

