Witness Name: GRO-B

Statement No: WITN0883001

Exhibits:4

Dated: August 2019

## INFECTED BLOOD INQUIRY

	Addition As a second of the se		
	FIRST WRITTEN STATEMENT OF	GRO-B	
l, GRO-B	, will say as follows:-		_

# Section 1. Introduction

1.	My name is GRO-B I wa	as born on	GRO-B	1970. I live	at GR	0-В
	GRO-B	I live	with my tw	o children,	GRO-B	and
	<sub>GRO-B</sub> who are aged GRO-B I have b	oeen working	as a	GRO-B	for the	last
	year and a half.		<u> </u>		.=.4	
2	My father, GRO-B was b	orn on GRO	о-в 1943 а	nd died on	GRO-I	3
	2019 after being infected with Hepatitis	C through co	ntaminated	blood produc	ts. My fa	ather
	provided his own statement to the Ir	nquiry prior	to his deat	h, under St	atement	No.
	GRO-B					
	,					
3.	My mother, GRO-B and sister,	GRO-B	nave also pro	ovided witnes	s statem	ents
	to the Inquiry under Statement Numbers		GRO-B			
	i.	l		!		

4. This witness statement has been prepared without the benefit of access to my late father's 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 Affected

- 5. Growing up I lived with my siste GRO-B who is 18 months older than me and my parents who were so in love. I have countless memories of us travelling abroad as we often did and taking part in various sporting activities. Both my parents participated in the GRO-B and my father loved his football, playing 5-a-side regularly with his friends.
- 6. My parents worked very hard and my father was in the prime of his career. He gave his family a wonderful life and being able to provide for his family gave my father a sense of pride. He was strict when needed and his ethics were sound. He was a gentle giant with a warm presence and made me feel safe and loved. He was always smiling and had a terrific sense of humour. He was a fair man who was loved by many and always knew there were two sides to every story. We would spend time at our beach-hut and fish from the boat; it was a really enjoyable time and we laughed a lot. We were a very sociable family, taking part in many different events, such as family orienteering in New Forest, cycling and taking our dog on wonderful walks on picnics. Life was good. However this all changed in the early hours of GRO-B 1986; the life my parents and our family faced was suddenly a very different one.
- 7. In 1986, my dad went to GRO-B after receiving a minor sporting injury to his eye. He underwent X-rays and observations whilst in hospital and, as a mild haemophiliac, was advised to stay in the hospital overnight. My father was aware of the risks of receiving blood products from what he had seen in the media and as such made it perfectly clear to the staff at the hospital that under no circumstances was he to receive Factor VIII concentrate. This was made clear to the hospital and in front of my father's friend, GRO-B GRO-B An account from my father's friend's son, GRO-B has been exhibited; WITN0883002, as to the events that occurred that day.
- 8. This plea was ignored and around 1am, he woke to the feeling of being pricked in the arm and to find that Dr Radford had already set up an infusion of Factor VIII concentrate. My father was unaware of what was happening until it was too late. Dr Radford assured my father that Factor VIII concentrate was perfectly safe and administered four bottles in total; three Armour and one NHS. We later received confirmation that the products were not safe and that the infection attributed to the care he received on this night; please see exhibit WITN0883003.

-	GRO-B	and WITN0883005.
	GRO-B	confirming my father had been given "hepatitis," albeit crossed out;
	tests.	GRO-B the medical record from
	received Facto	r VIII concentrate which held a risk of Hepatitis and advised a series of blood
	wrong with hin	m as he had received a letter from Dr Radford stating that my father had
	him flat on his	back due to the severity of the illness GRO-B new immediately what was
	jaundiced, seve	erely fatigued and very poorly. His GP GRO-B came to the house to see
9.	. Six weeks afte	er receiving these blood products, my father became very unwell. He was

- 10.I remember clearly being given the news. My father sat my sister and I down and told us in the best way he could. I could see in his eyes that he was upset. I felt like my life shattered there and then. My father, the strong man with a wonderful career, who really did make the most of his time on this planet and was the man who lit up any room; was suddenly going into darkness.
- 11. The GP told my dad there was nothing he could take to alleviate the symptoms; his body would have to fight it. My dad was told about cross contamination, if he had a cut, he had to cover it up. He was also told how this could develop into cirrhosis and eventually liver cancer. He would hide his razors and toothbrushes as he was worried we would pick them up by mistake. My father did a lot of research himself because he wanted to keep himself as informed as possible.

## Section 3. Other Infections

- 12. My father was tested for HIV but fortunately this test came back negative.
- 13. My father received a letter telling him that he may have been exposed to vCJD. However there is no test for vCJD whilst alive, so he spent the rest of his days not knowing if he had the virus.
- 14. There were no tests that could have been completed whilst he was alive, so when my father died his brain was sent to Edinburgh so the relevant tests could be carried out. We are still awaiting the results.

## Section 4. Consent.

- 15. My father consented to be tested for Hepatitis C by his GP, but his treatment of Factor VIII concentrate in the first place was against his wishes.
- 16.I believe my father was tested for the purposes of research. I saw a documentary on BBC Newsnight, called "I was infected by contaminated blood when I was 5" whereby the victim had seen letters stating that it was cheaper for them to test on haemophiliacs than it was on chimpanzees.

# Section 5. Impact

- 17. I have suffered from clinical depression for a long time and as I now know, this goes back to my late teens. I have battled with this illness for many years. I am on medication and still struggle with life. I am still having various forms of therapy to help me with day to day struggles. I find it hard to maintain employment and relationships due to my illness. I still feel very insecure and vulnerable. I can't say 100% that my father's diagnosis was the major contender but I am certain this has contributed to my illness and the life I have had.
- 18. My father was never the same person after being infected. He could no longer play football or squash, so took up a more gentle sport, golf. His concentration levels were affected, he lacked energy and ill health forced him to undertake part time working hours. His health quickly deteriorated over the years and he suffered from endless problems relating to Hepatitis C.
- 19. In an attempt to clear the virus, my father underwent four different courses of treatment. He was first treated with Interferon in December 1995 and after this failed, was treated with Interferon and Ribavirin in 2000. These attempts failed to clear the virus so he later received two courses of Ribavirin with Pegylated Interferon. None of these bouts of treatment worked either.
- 20. The mental and physical effects of these treatments were apparent. When given Interferon it made him really poorly and he was too ill to finish the course. The Ribavirin gave him severe breathing problems and I remember on many occasions when I could hear my father struggling for breath. I remember him really struggling when on these treatments.

- 21.My father also underwent five courses of TACE in an attempt to reduce the growth of the liver tumours. He suffered from ascites which meant he needed to have litres of fluid drained from his stomach every week. Seeing him suffering was horrible. He was always the rock of our family and had always made us feel so secure.
- 22. By September 2018, my father only left the house to attend the hospital. Each visit to the hospital severely reduced his strength and he grew weaker and weaker. He could not walk and his head had to be supported in the latter stages.
- 23. On his final trip to the hospital, he had a tube directly stuck into his stomach held by a stitch to have a permanent drain fitted to drain his ascites. The risk of infection was extremely high but my dad had no choice; the time between having his ascites drained was getting shorter and shorter. The tube looked so uncomfortable but he never ever complained. He was very much cared for by my mother and I am sure this care contributed into his living as long as he did.
- 24. Unfortunately he lost his battle on GRO-B 2019 and died at home in his bedroom with his family around him where he wanted to be.
- 25. Even after his death, issues arose. My dad could not be clothed; his clothes could only be laid on top as his body was zipped up. He was denied a natural burial and couldn't be embalmed. His post mortem could only be carried out at Southampton; in a high risk department where they carried out post mortems on drug addicts and bodies with a high risk of contamination. His brain had to be removed and sent to Edinburgh to be tested for vCJD. I found how my father's body has been treated after death to be very upsetting.
- 26. The stigma he suffered when he was alive was awful too. I remember feeling really upset for my dad when he went away on his golfing holidays and no one wanted to share a room with him which made him feel so isolated. Unfortunately, people are ignorant and the stigma attached was very distressing at times. My dad had skull and crossbones drawn on his mug at work to warn people not to use it. His work colleagues would say that he had sex with a monkey which was how he got Hepatitis C. This was extremely upsetting and my poor lovely father just didn't deserve this behaviour. We were the leper family and some people just didn't want to be associated with us.

- 27. All the while this was going on I was doing my GCSEs at the time and I really struggled. It became very difficult to focus with everything going on at home and my concentration levels were poor as all I could think about were my poor parents. My mother had to go out to work full time and I took over the household chores. As such, I didn't get the grades I needed to go on to study a Media, Hair and Make-up course and I just had to find work instead. I was eventually able to go back to college in my mid-20s.
- 28. The financial effects this had on our family were a massive black cloud. My father had earned a fantastic salary before he was infected and was able to provide his family with a truly wonderful life. The house deteriorated as no money could be spent on it and if the washing machine broke this could not be replaced. All the usual things which broke or needed replacing couldn't be done as we were only getting Statutory Sick Pay. Not only was his health taken away from him, but his pride too which made him depressed.
- 29. Not only have I lost my father, but my children have lost their grandad and my mother, her best friend. He was a typical loving grandad, full of smiles and hugs. They were lucky to have him and it has been really difficult on them to lose him too.
- 30. My son is a mild haemophiliac and after what happened to my father, I cannot even convey how very nervous I am about my son receiving treatment.
- 31. My dad was a true gentleman through and through. He faced his illness with such courage and bravery and we all feel our dad was robbed of his life and wellbeing. The world is certainly a very different place without him and will never be the same. My dad simply didn't deserve any of this, he was kind, fair and had a lovely aura and all who came into contact with him remembered as the lovely man he was.

# Section 6. Treatment/Care/Support

- 32. It was difficult for my father to receive dental treatment as the dentist would only see him at the end of the day, due to the fact he had to either throw instruments away or sterilise everything which wasn't cost effective for him. He later changed to a dentist at the hospital.
- 33. My father also needed a knee replacement after injuring his knee, but this could not be done as he was deemed to be 'high risk' and therefore only able to take a few paracetamol

to alleviate the pain. He hobbled around for years that way in pain, but somehow he still had his sense of humour.

- 34. He was eventually offered counselling which he took up. He did feel that it helped him with his struggles and was glad to have some help, although he would have benefited from having this help earlier.
- 35. After my father's death, the Macmillan team told us there was counselling available if we needed it. We had one group session and were told we could go back anytime, which we found really helpful.

### Section 7. Financial Assistance

- 36. My father was one of the first people to take the NHS to court for treatment with infected blood products. It took years to get an out of court settlement and my father had to sign a waiver to receive it, although at this time this was all in its infancy and the true scale of the horror had not yet been revealed.
- 37. My father received some financial support from the Skipton Fund, which he was advised to apply to by his haematologist.
- 38. My father was made to feel degraded and humiliated by the DLA. He was made to go in front of an appeal panel to ask for financial support. This process needs to be changed; these people are human beings who have been left with a death sentence and a debilitating life through no fault of their own. They should not be constantly questioned they should be awarded the payments for life so they don't need to repeatedly go through the process. My father was at the end of his life and still had a form that had to be completed to prove his ill health; it's a disgrace.
- 39. We have had no problems with EIBSS at all. Monthly payments were stopped a few weeks after his death and my mother received the Widow's Payment.

## Section 8. Other Issues

- 40.1 think that the spouses of the infected need to be supported and financially secure. Those who are infected should also be given appropriate care at home when needed at the end of their life.
- 41. The truth needs to come out, people need to be held accountable and apologise for what they have done. We want justice for our dad and all others who were given this death sentence. We want justice for the spouses whose lives were changed, as they need looking after too. This was one of my father's worries for my mother, as she had been a devoted wife and loved him deeply and he would have hated the thought of her struggling.
- 42. We have been robbed of a father, husband and grandfather for something which could have been avoided. I feel very angry about that. My dad really did suffer for many years mentally and physically, this in turn has had a devastating impact on our family.

# Anonymity, disclosure and redaction

- 43. I GRO-B wish to apply for anonymity.
- 44. I would be happy to give oral evidence to the Inquiry.

#### Statement of Truth

l believ	e that the facts st	ated in this witness statement are true.
Signec	GRO-B	
i. Dated	25.8.19	i