Witness Name: GRO-B

Statement No: WITN6607001

Exhibits: N/A

Dated: 18 October 2021

# INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

# Section 1: Introduction

- 1. I, GRO-B
  DOB
  GRO-B
  of
  GRO-B

  Essex
  GRO-B
  will say as follows:
- 2. I am the daughter of the late **GRO-B: F** who tragically contracted Hepatitis C arising from the receipt of contaminated Factor concentrates.
- 3. My father suffered from mild haemophilia. This is not something he or the family were aware of at the time of his procedures as he had been fortunate in avoiding all issues relating to his Haemophilia status up until his admission to hospital in or around 1985.
- 4. On GRO-B 2020, my dad was admitted into Conquest Hospital by ambulance after vomiting blood. He underwent an endoscopy to examine the cause and attempts were made to cease the bleeding from his oesophagus. He was diagnosed with cancer on the same day. He was transferred to palliative care at a hospice on GRO-B and died two days later of sepsis and cancer.

## Section 2: How Affected

- 5. In or around 1985, my father was admitted to Conquest Hospital in Hastings for observations following a small bleed. Sadly, his situation was misdiagnosed and he underwent what later proved to be unnecessary procedures and operations which intensified his bleed, to an extent that it became uncontrollable. Unable to identify the cause of the continuing bleed, he underwent a Laparoscopy. This was followed by two surgeries removing parts of his stomach as **GRO-B** had made a diagnosis of cancer following a review of my father's X Ray results. It later transpired that my father never had cancer. Also, due to no action being taken about his continuous bleeding, my father contracted Septicaemia.
- 6. My father was continuing to lose blood. This situation was disturbing as the hospital was doing nothing to identify the cause of the bleed and instead put it down to trauma. My father's bleeding became that bad that it led him into intensive care fighting for his life. He had several blood transfusions. It was not until my mother was assisted by a Physician, who saw how distressed she was at the Chapel, that he offered to help and suggested Haemophilia as a cause of the bleeding which finally led to a diagnosis. Unfortunately, the diagnosis was too late as he had already gone through so much trauma with three unnecessary surgeries and the removal of his stomach.
- 7. My father was treated with all sorts of blood products, including Factor VIII, which finally stemmed the bleed. Sadly, he came out of this having contracted Hepatitis C, although this was not diagnosed until much later.
- 8. The rest of the family were tested for Hepatitis and indeed somewhat fortuitously, the test results were negative.
- 9. Around 2000-2001, my father was treated with Interferon for his Hepatitis C infection. This was a very difficult time for the family. I recall how painful it was

to see him suffer from the side effects of Interferon treatment which effectively made him bed bound.

#### Section 3: Other Infections

<u>N/A</u>

## Section 4: Consent

<u>N/A</u>

## Section 5: Impact

- 10. As a child, I remember my father as a strong and active man, laughing and playing with me and my sister. After he returned from the hospital, he became frail, wheelchair bound, depressed and always ill. His health deteriorated further over the years. He was throwing up blood, couldn't eat, would not play with us, could not take us to school and became depressed. I would always draw comparisons with other children and feel sad that I could not have that interaction and support of my parents as they were too busy dealing with my father's ill health.
- 11. From a very young age I became a carer for my father, a responsibility equally shared with my mother and sister. From the age of about 5 or 6, I would frequently have to ring the emergency line for an ambulance for my father. The stress of being a carer meant having a difficult childhood, being absent from school frequently for medical emergencies etc. There is also the extreme anxiety that comes with having a desperately, chronically sick parent. There has never been a time in my life since childhood when I was not worried that my father would not be there in the morning when I woke up.

- 12. The overall circumstances have had a profound effect on my physical and mental well-being. I remember being worried all the time and not wanting to go to school, bottling things up inside, not telling any-one what was going on. I did not know how to express myself and feared being judged. I did not feel anyone would understand. It was like living a double life from a young age and this has scarred me for life. To this day I feel unable to deal with situations in life. It made making friends difficult and any friendships I did have could not be normal as I could never bring them home or share things about my life.
- 13.1 experienced bullying at school because of my fathers' illness. All sorts of rumours were circulating about my father's infection and illness, where it had come from, and this resulted in me being very much left apart and isolated from everyone. In turn, this impacted my self-esteem and confidence growing up. These are important years of a child's life when a personality is developed, but this situation has left me traumatized.
- 14. Due to the abuse my **GRO-B** and I suffered growing up, and to avoid the consequence of our father's viral status, we both changed our names so we could not be identified as part of the family. It is unfortunate and hurtful that we had to distance ourselves from our father in this way, when in reality, we shared a very close bond.
- 15.1 was unable to par-take in any extracurricular activities, as I had to care for my parents. I really wanted to go dancing but my parents could not take me, plus my time was taken caring for my sick father and mother who was not doing well, given the challenges of my father's ill health and additional responsibilities she was burdened with.
- 16. I had to learn things on my own as my parents were unable to be there for me as much as they would have liked. They never attended my parents' evenings. I felt I missed out on their support and guidance which would have

been of considerable use to me even into my teenage years. I felt I had to guide myself and my learning came from outsiders.

- 17.1 am always worried about my sister's health and wellbeing due to the impact of our family situation on her. My sister was also a carer for my father, and she took on the responsibility of things like administering my father's injections, whilst I would provide other care and financial assistance. She has not coped well emotionally and I am concerned about the impact the stress has had on her over all these years.
- 18.1 completed my A 'levels but feel I have underachieved and not reached my educational potential. I had dreams to go to University and despite enrolling on a <u>GRO-B</u> and repeating the second year, I was unable to sustain this, and had to drop out due to my father's ill health, which at that time, was so bad that he had attempted to commit suicide.
- 19. At the point of my dad attempting to commit sucide, my sister's and mother's mental health declined. It was another turning point in our family, and it sent us into an emotional tailspin from which I never fully recovered from. This had a profound effect on my emotions and life. There was no one to turn or talk to about the situation. Which I found extremely difficult and painful. At the same time I was assaulted at university. It was something I was unable to speak to my family about due to their stress and ill health.
- 20. If I had had the opportunity, I would have wanted to go to Art School and become a fashion designer. I have had to alter my career choices. Money was very tight due to my father's loss of career, and I therefore had to support him. This meant my focus was on just getting into work and holding down a job, rather than exploring opportunities which I would have wanted to pursue. I currently work in **GRO-B** but this is just a job that came along and not one I wanted to pursue long term. I am, to this date, under stress to make ends meet. I feel I have missed the opportunity to pursue my

choice of career and feel it is now too late to do so. I was offered unconditional places at both **GRO-B** for art and design but was unable to take up the offers due to course costs. In any event it is not something I can or could afford.

- 21. The impact of the stress on my physical and mental health has been immense. The pituitary gland on my right side is swollen. I have constant severe headaches for which I have had three MRI's and the investigations are ongoing. I lost a lot of weight, going through possible early menopause and have resorted to heavy smoking. I have had severe problems with my teeth due to what is believed to be caused by hormonal changes and clenching my teeth when stressed. I can not afford the treatment and they are slowly breaking, falling apart, or already gone. I am terrified of medical staff and hospitals and continue to have nightmares.
- 22.1 have neglected my own health by not discussing any of my family issues, or its impact on me with my GP. I always feared that if I spoke to my GP, it may result in me not being able to work if I was signed off sick. Being out of work, was simply just not an option for me in my circumstances.
- 23. At one point I was even diagnosed with ME. At the time that I enrolled at University I tried go for counselling, but after a couple of sessions I did not continue with this as I did not feel it was helping. When living in hostel, they tried to offer me counselling, but I again refused for fear that it would get in the way of my work.
- 24.1 fell pregnant at 21, but I was too scared to bring a child into the world. I was worried the child may have haemophilia, worried about the risk of cross infection, felt I would be unable to cope mentally or financially. I knew my parents would not be able to support me, plus I did not know where we would live. All my fears resulted in me terminating my pregnancy.

- 25.1 was always a person who wanted to get married and have a family but cannot see this ever happening. It would be impossible for me to sustain a relationship; I cannot trust anyone and am always worried about bringing trouble home. I am extremely guarded, emotional and occupied with work, which has further impacted my ability to have relationships.
- 26. I continue to struggle financially and housing has always been a struggle, to the extent that I have been made homeless three times. No support has been made available to me.
- 27. My father was rushed to hospital by ambulance around 5pm on **GRO-B** 2020 after vomiting blood. It took 40 minutes for the ambulance to arrive. No-one was allowed to accompany him because of coronavirus restrictions.
- 28. On **GRO-B** 2020 he was released from hospital and arrived back to his home at around 6pm however his health continued to deteriorate at a rapid rate. I was dealing with everything via phone calls and I was told that he had began hallucinating. At this point I realised that the hospital had made a mistake sending him home. My sister and my mother were both extremely distressed, panicked and dealing with the severity of the situation on their own with no outside help or care which devastated me.
- 29. On **GRO-B** 2020 he was once again rushed to hospital at about 5am after vomiting blood. Again, no-one was allowed to go with him. Later on that day my father called and informed my sister and mother that he had cancer and a problem with his oesophagus. I was informed by my sister. An Endoscopy was arranged for the same day, but nothing could be done as he was too ill and it was too risky. Palliative care was required. Palliative care was arranged by my sister and mother overnight because the hospital palliative care team were on holiday due to the bank holiday weekend that was coming up at the time.

- 30. On **GRO-B** 2020 my sister and my mother were allowed to visit my father at Conquest Hospital, one at a time and only for 15 minutes at a time. I was not allowed due to restrictions as I lived in London.
- 31.On **GRO-B** 2020 my father was transferred to the hospice in the morning. My sister and mother were allowed to visit after 5pm. Only one family member could be in his room at a time and only one could stay overnight so my sister stayed. My family asked if I could visit, but they said no. London was considered a coronavirus hotspot and they did not want visitors from outside the hospital trust area to visit. My mother appealed, but the head of hospice said the decision was final.
- 32. Or **GRO-B** 2020 my father died at 11.21 am from sepsis and cancer. My sister was on her own with him when he passed away. This has been extremely traumatic for her.
- 33.1 can't adequately put into words the amount of distress and hurt that my fathers illness, his continued suffering through the years and his death has caused. I will forever struggle with this loss, trying to come to terms with it. I remember when I was child understanding that there would be sadness in my life. That I would lose my father and most likely consequently lose my mother and sister too. That it would only be a matter of time. I watched them each battle with mental illness and health problems. My father's illness took over every aspect of all our lives. My life has been filled with anxiety and fear. I worked long hours through the night to make sure that I was able to care for him and be there during hospital admissions. I learned to struggle alone so as not to burden my parents with more stress.
- 34.1 can't come to terms with how the world could be so cruel, and even in my father's death he was let down by doctors over and over again. His health declined rapidly in a very short amount of time. He was so devastatingly ill and tired. There was no time to process what was happening. Leaving us all

in shock. He passed away in fear and confusion. It happened during lockdown, he was not surrounded by all his loved ones. He passed away not having peace of mind. He did not know or have any certainty that any of us would be okay. My father passed away before I could see him one last time. That opportunity was taken away from me. Memories haunt me every hour of every day as I try to come to terms with it all. After all the struggles and devastation, I've been left with questions that will never be answered. Why did this happen and why did it end like it did?

- 35. The months that followed his passing have been extremely dark and left a severe void within the family. My mothers and sister's health has declined dramatically. I have struggled with my own mental health and have found maintaining work difficult, sliding further into debt.
- 36.1 grieved the loss of my father completely on my own in London during lockdown without friends, colleagues or family. It has been an extremely lonely and painful experience that I did not know how to handle. There has been no help, support or care.
- 37.On 1 July 2021 due to spiralling debt and difficulties in maintaining work and my own mental health after the loss of my father I left my rented studio flat in London and rented a small room instead.
- 39. My life has been spent working, making savings then losing them each time my father fell ill and was rushed to hospital. I tried helping out as best as possible and took out loans from banks or other financial institutions so that we could survive but it wasn't ever enough. And after paying those back; the cycle would repeat.

40. The circumstances of my father's illness have left an indelible mark upon my life, my personality and my opportunities. Myself and my family have been left traumatized by the level of stress we have been put through. The upset the situation has caused over all these years, through no fault of our own, has left many questions to be answered.

## Section 6: Treatment/Care/Support

41. The government has provided insufficient support at all levels which has resulted in me becoming homeless, caused extreme financial hardship, hindered my educational and career prospects and damaged my mental health with no emotional being support available, by way of counselling or otherwise to assist with the stress.

## Section 7: Financial Assistance

- **42.** As far as I know, my father was in receipt the Hepatitis C stage EIBSS monthly payment from 2016 onwards.
- **<u>43.</u>**My mother had to sell her business and our home to assist my father financially. Up until the time of his death, he was fully dependent upon the UK Government.

## Section 8: Other Issues

44 Clearly, there has not been enough understanding of the impact of the disaster on those Infected or Affected, and although this Inquiry is inexcusably delayed, I hope it would bring some accountability, changes to the system and justice.

# **Statement of Truth:**

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

Dated the		18th	day of	October	2021
Signed:		GRO-B			
	GRO-B				