

Witness Name: **GRO-B**

Statement No: WITN1607001

Exhibits:0

Dated: March 2019

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** DOB **GRO-B** and I live at **GRO-B**
GRO-B with my husband and three daughters.
2. My father, **GRO-B: F** DOB **GRO-B** died on **GRO-B** at the age of 50 after being infected with HIV as a result of treatment with contaminated blood products.
3. My mother has provided a witness statement to the Inquiry **GRO-B** and my siblings also intend to provide witness statements.
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. Dad had severe Haemophilia A and was infected with HIV following treatment with Factor VIII concentrate.

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6. I was a teenager when I was first told about my father's illness. Mum only told me and my older brother as my other brothers were too young. Initially the advice was to be really careful around Dad. We were advised not to share toilets and not to use his cutlery or toothbrush.
7. I still remember my Mum's absolute fear when she told us. There was such a stigma at the time, she was so scared of people finding out and what would happen if it did get out. Mum and Dad had been warned by medical professionals to not say anything so it was just a dark secret that we had to keep. It was like having a black cloak over our lives.
8. As Dad's illness progressed we later discovered that he had also been infected with Hepatitis C.
9. Information about how my Dad was infected is set out in my Mum's statement.

Section 3. Other Infections

10. I am not aware of any other infections that Dad may have been exposed to.

Section 4. Consent.

11. I am not sure of what testing Dad consented to.

Section 5. Impact

12. Our family was devastated by the news of Dad's infection. The subsequent years of his protracted ill health and the fear of the stigma had a traumatic effect on us all.
13. Mum and Dad were very sociable people. There were always lots of visitors, social events and dinner parties and we were a very busy, active family. We were GRO-B children who always had friends round and it was a busy, full house. That all changed when Dad found out about his illness. Nobody came to visit, we didn't invite friends home anymore and there were no more dinner parties. The isolation was dreadful.
14. As a child it was a really difficult balance of not wanting to upset Dad but also being scared of the infection. Things like sharing food and giving him a kiss goodnight suddenly made me

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worried, and that fear was a horrible feeling. It felt awful to not want him to take a spoon of my cereal in the morning or to wipe my face if he kissed me and his beard was a bit wet. It was a very frightening time of conflicting emotions and all trying to protect Dad's feeling, whilst suppressing our own.

15. I know that Mum had to be tested every year to check her HIV status and at the back of our minds we were worried about her also being infected.
16. The stigma surrounding the virus was awful. Everyone made jokes about AIDS at school and I remember seeing the tombstone adverts on the TV. Dad would come home and share the jokes he had heard at work and it was crippling hearing him say them. We would all try to laugh but inside it hurt and knowing how much it must hurt him too was heart breaking. We heard stories about people who spoke out about the illness being targeted and abused; Mum was therefore incredibly worried about people finding out, as were we.
17. I felt like such a fraud at school. I had a friend who was a big Freddie Mercury fan and she was very upset when he died, but I wasn't able to share the truth of my life with her. It made everything feel very shallow and meaningless and was hugely isolating. It was hard to share anything with people knowing you were keeping such a huge secret from them.
18. I think we all knew in our hearts that Dad had maybe ten years maximum to live, but no one ever articulated that to Dad. He always had the outlook that he was going to beat HIV. We all saw signs of his deterioration but we just had to pretend that everything was normal. That was the hardest part, pretending that everything was alright and not being able to talk about it. Dad was a proud man. He had fought the restraints of his haemophilia all his life and always refused to have a disabled badge. He refused to accept that HIV would kill him.
19. I was academically strong at school and I was pushed to do A Level science. However, when I was at sixth form there was so much going on at home that I never really got the opportunity to sit down and think about what it was I wanted to do. I do not know what I would have ended up doing if I had been afforded that time, but I felt like Mum just needed to see me go to university so I went into teaching. Dad had always encouraged us and pushed us to be the best we could so he was keen for us to go to university.
20. I went to GRO-B and studied GRO-B I was so torn whilst I was there because I was constantly worried that I would have to rush home because of Dad's

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illness. I never really got to embrace and enjoy university life and I was unable to share the truth with any of my new friends. They would be out enjoying themselves and I felt constantly constrained by my family's secret and my worries about Dad. I felt 'lost' and isolated.

21. When I qualified I moved back to GRO-B so I could be closer to Dad and got a job locally as a teacher. I just wanted to help Mum as much as possible, which meant I would go straight to Mum's after work, do what I could to help, stay over and then go to work in the morning.

22. At one stage Mum was offered assistance and agreed to try for one night. The young carer sent round to help stood at the end of Dad's bed and said 'has he had his nappy changed?'. After that Mum wouldn't have anyone round to help care for Dad.

23. We lost Dad long before he passed away. He lost his speech, he had changed so much. Gradually he became a living skeleton. It was a slow, painful decline; we had to help Mum take him to the toilet and wash him. It felt disloyal to admit it, but eventually when he was so ill and everyday seemed like it would be his last, it felt like we were waiting for him to die. When I went into the room to visit I used to hope that he would be asleep because he would try to talk to me and often I wouldn't be able to understand what he was saying.

24. The day Dad died I left work and went straight home. The funeral directors had said once his body was put in the casket no one would be able to see him, so he was kept at home whilst family said goodbye to him. The stigma and fear around the disease meant there was no dignity, even in death. His body was treated like a piece of contaminated meat.

25. Mum handled all of the funeral arrangements and I remember sitting on the stairs on the day of the funeral with my siblings and waiting for everyone to leave. There were a lot of people at the funeral and I remember feeling a sense of anger that none of them had bothered to visit him in the last few years. Where had they been?

26. I suffered from anxiety, depression and an eating disorder which started in my first year of university. I started to self harm in my first year of teaching. I worried that if people found out that Dad was HIV positive at the school then they would not want me teaching their children. After Dad died I was feeling increasing anxiety, my health was suffering and I just felt hopeless.

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27. I hit rock bottom in or around 1999. I found myself driving in my car and just not wanting to go home. I thought I about driving my car into something to end it all. I cut myself off from my family and left my job. I tried to commit suicide numerous times. This was made worse by the fact that I had developed such a deep distrust of the medical profession that I couldn't bring myself to seek or accept help even when my family tried to intervene.
28. I ultimately had to give up my job, at which stage I obviously had to go to my GP. They suggested I do some Cognitive Behavioural Therapy. I tried this but when I went to sessions I found I was selectively mute; I would turn up and want to speak but I just wasn't able to get the words out. I could not articulate all the things I had internalised for so many years and did not believe that the counsellor would understand or be able to relate to it.
29. I met my husband in 2003 and we married in 2004. It was this relationship that finally gave me hope for the future; something that had been missing in my life for some time. As a carrier of the haemophilia gene I was very worried about the prospect of having a son and him going through a similar thing to Dad (and whether, if I was having a boy, I would be able to go through with the pregnancy); luckily we have been blessed with three daughters.
30. The stigma around HIV is still strong and I am worried about my girls and how this might affect them in the future. The only situation I have found it vaguely comparable to is the fear attached to the Ebola outbreak, but at least that virus went without the sleazy connotations and the element of 'fault' that accompanied the initial outbreak of HIV. Things have moved forward a lot and attitudes are more informed but there is still fear and connotations attached to HIV that I don't want my daughters to have to handle.
31. Towards the end of Dad's illness and following his death I felt socially isolated, I felt like I wasn't going to have a future or a family or children. As such my confidence was affected massively. Even now I think my family are very different to the people we would have been if Dad had not been affected as part of this Scandal. We were such gregarious and adventurous children but we have all changed as a result of having to keep people at a distance and the enforced secrecy that dominated our childhood.
32. Dad was a GRO-B and he was doing very well for himself, however when he started to become ill we struggled as his income was mainly made up of commission. We had a big family house and we were comfortable financially, but after Dad died, Mum had to

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start working again to provide for herself and us children. She also had to sell the family home and downsize.

33. I am currently a part-time tutor and one of the things stopping me from going back into teaching is having to explain the gap in my career and confront my history.

34. Dad never got to meet my husband or his grandchildren. I want to be able to tell my daughters about their Grandfather but we have decided to wait until we are sure they are able to understand and process everything. I am now approaching the age that Dad was when he died. It really makes me realise how incredible my Mum was for raising five children whilst her husband was dying and how premature his death was.

35. Even after his death, nine years after we were told of his infection, we were left struggling with the legacy and still today bear the emotional scars of the whole ordeal. My Dad was a hard-working, proud, independent man who was determined not to be defined by his haemophilia, or even his subsequent health problems caused by infected blood products. To think that all of this was avoidable is very hard to accept.

Section 6. Treatment/Care/Support

36. We weren't offered counselling or support as children. When Dad died we were offered bereavement services and family counselling through the hospice, but at this time it was way too raw and it was too broad – they wouldn't have had a clue about everything we had been through and the sense of isolation we felt. We needed specialist help from people who understood the background to Dad's death; not just standard bereavement counselling.

Section 7. Financial Assistance

37. I believe that Mum had some support from the financial schemes which she has tried to share amongst us.

Section 8. Other Issues

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38. I was watching the Hillsborough coverage and there was someone being charged for manslaughter for making bad decisions on one day. With the infected blood products scandal, we are talking about numerous people at a very high level making decisions that killed thousands of people. They were economic decisions made by people that destroyed the lives of ordinary, hard-working people who were trusting them to provide vital healthcare, and the Inquiry must ensure that these issues are thoroughly investigated.

Anonymity, disclosure and redaction

39. I would like to apply for anonymity.

40. I do not want to give oral evidence to the Inquiry.

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Statement of Truth

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

Signed...

GRO-B

Dated...

25-3-19