

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN5693001

Exhibits: N/A

Dated: May 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B says as follows:

Section 1: Introduction

1. I make this Statement for the benefit and assistance of the Infected Blood Inquiry relating to the circumstances surrounding the death of my father, GRO-B:F F who was born on GRO-B and sadly and unexpectedly passed away on GRO-B 2019 at the age of 63.

Section 2: How Affected

2. My dad was always a very positive person when I was growing up. I believe that he was diagnosed with HIV in October 1985 and from this point onwards, his life and my mother's life was changed forever.
3. Due to the stigma and fear surrounding HIV, my parents were petrified about their future and that of our family.
4. I was born in 1986 and my dad begun his treatment for HIV in the 1990's, but it was not until my teenage years that my dad made me aware of his status due

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to his worry of how it would affect my life and I believe that he tried to protect me so that I would not be excluded during my daily life due to the stigma.

5. From an early age, I was aware of haemophilia as my dad talked to me about it as he often wore shorts and a tubigrip bandage due to frequent bleeds in the one knee causing it to be swollen regularly and painful. He also regularly used walking sticks when we went out and about.
6. I recall sitting with my dad when he administered his home treatment, which was kept in our fridge and a sharpes bin was always kept in the garage. I was able to help him during this routine by taking off the coloured lids of the treatment and then I would write his levels on his record sheet.
7. During the course of my primary school years, dad had a few knee operations and so I was used to him having time off work to recover in the house and do physio.
8. It was when I started my first year of high school when my dad had to start taking treatment to keep the HIV under control and along with the physical presence of lots of different tablets, he also needed to carry them around with him as he took them at different times of the day. He did this as discretely as possible as only mum and I were aware of him being on medication.
9. The tablets came with many various side effects, however the following had a profound affect and so they standout in my memory:
 - Weight gain / bloated appearance
 - Yellowish skin tone
 - A lot of sweat (enough to have to change t-shirt etc)
 - Alopecia
 - Alone / isolation / feeling useless
 - Fear / Scared
 - Dark / Suicidal thoughts
10. The medication and side effects contributed to my dad's mental health as it was a constant reminder of his HIV status. Despite my young age, I know he worried about the side effects and the potential problems the medication might have to his wider health in the long term.

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11. He became quite depressed, he became very anxious and he found it hard to deal with life's daily obligations. This ate away at his confidence and what was once a very positive man, he became consumed with negative thoughts.
12. As a family we lost our relationships. My parents withdrew into themselves and became their own little unit. I will always regard this time as when I lost my dad to a deep dark depression and ultimately to the illnesses.
13. As a result I believe I matured a lot quicker than my teenage peers. At such a crucial time in my life I took on role of being a protector and became carer for my parents as I witnessed their relationship deteriorate.
14. Despite struggling to be a normal teenager and wanting to be a support for both of them when my dad's depressive episodes were at their most severe, it forced me to grow up very quickly, to become an adult before I was ready and to adapt to a home life where I became a carer to comfort them both.

Section 3: Other Infections

15. I believe my dad was infected with Hepatitis C as previously stated in my statement we only had a couple of conversations around his status regarding HIV and other infections contributing from this diagnosis.

Section 4: Consent

N/A

Section 5: Impact

16. I became acutely aware of the decline of my dad's mental health. He plunged into a deep dark depression which would involve him isolating himself, wanting to be in the dark and lying down. His depression changed his personality and caused him to be very angry and short tempered.

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17. I am now aware that during the course of my life my dad made a few failed suicide attempts, when these incidents happened I was unaware of his status, so I didn't understand the inner turmoil he was feeling or why he would want to leave us. His first attempt was when I was 11. I went home after school to find him after taking an overdose. On another occasion, an attempt resulted in him being admitted to **GRO-B** which provided inpatient mental health care. This deep dark depression lasted for all of my high school years, firstly affecting my education and meant I only opted to only do the core GCSE'S, and it impacted on me significantly as it meant like other family's we didn't have an open house for my friends to come and stay over as I didn't know what my dad's mood was going to be like.
18. This lead to me being very isolated from my peer group and often meant I was excluded from social events / meet ups. I was quiet and had withdrawn into myself. I learnt to contain our family secret like I watched my parents do, as they thought it was protecting us from the backlash and stigma circulating at the time. It was a very difficult time, as we all tried to carry on with our lives of work and school.
19. My dad had forged a successful career in the insurance industry despite his diagnosis. He continued to strive to live and have normality which had been taken from him at a young age. This had a knock-on effect to myself despite my parent's best efforts to give us a good and happy life. As a family infected and affected by the blood scandal, we all carried a constant black cloud of secrecy and suffering with us every day.
20. In life and death, my dad fought a courageous battle against not only the symptoms of the illness but the mental burden of carrying them. I've watched him be discriminated against for all of my 32 years he was living with haemophilia and HIV following the infected blood scandal.
21. On **GRO-B** 2019, he died suddenly within minutes at home. The paramedics attended and spent nearly an hour trying to resuscitate him. He was then admitted to Warwick hospital.

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22. Initially, as there were no signs of a heart attack, we were told a post-mortem was going to take place. However, when the Coroners at Warwick Hospital became aware of my dad's status they then declined to carry out a post mortem due to not wanting to touch him. This information was relayed to us during several telephone calls. Furthermore, the hospital instructed the funeral directors not to dress him, just to place a gown over him. My mum had to insist to be able to see my dad and this was eventually granted on the 19th March 2019.
23. I cannot articulate how devastated my mum and I were when we realised that my dad had not been touched. He was still dressed in the same clothes he was admitted to hospital, along with his hearing aids and medic alert necklace still on.
24. My dad was transferred to Coventry Hospital as they said he needed to be at a haemophilia centre to be reviewed by a doctor who had seen him recently to sign the 1A form. The death certificate was issued to us, but we learned that there were issues with having a doctor sign it.
25. I contacted the Haemophilia Society who advised me to speak with the Terrence Higgins Trust due to the fact that it was the HIV status causing the issues. The discrimination that my dad, mum and myself experienced during his death was absolutely appalling.
26. The funeral directors that we engaged did try to help and support us and they showed empathy and compassion. They advised us they are bound by rules and regulations from the Coroner. My dad would have hated to have been in hospital for such a length of time and to be treated with no respect like he was an inconvenience who was contaminated.
27. This is unjust. He deserved to be able to be at peace. My mum and I deserved to be able to grieve and this has now left me with questions is this a common practice? I personally feel his illnesses contributed to his death either directly or indirectly together with all of the treatments and medication he was taking.

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28. The discrimination and stigma we endured continually resurfaced when my dad sought medical help or had procedures. This ranged from staff completely gowning up to the extreme, to side rooms and isolation with signs up warning of contamination / risk of infection. The most recent case of this was at Birmingham hospital where he was booked in for a bladder test (2018) which had required extensive planning for the hospital and for my parents. When they got to the appointment they were told it couldn't go ahead due to infection control needing to take measures and so he was advised to make contact with his haemophilia nurse specialist which he did immediately.
29. The following day I spoke to my dad where he expressed his frustration, annoyance and upset as these precautions should have already been put in place, prior to his attendance as it was requested by his HIV consultant. HIV status has often limited the healthcare, medication, treatments and operations that my dad and many others like him can access. Other routes, further investigations and areas of the NHS have to be spoken to and researched and this takes up time and can prolong the health issues.
30. Due to the sudden and unexpected death of my dad, we never got to really discuss all of his illnesses that were always there, hovering in the background ready to take hold.
31. It is with great sadness that I will never be able to express how incredibly proud I am for all that he endured, he fought a courageous battle on many levels throughout his daily life - it impacted on his marriage, as a father as well as work, colleagues and friends but ultimately his health. I am writing this out of love and to give my dad a voice as he deserves to be heard and it is time justice was served.

Section 6: Treatment/Care/Support

32. My mum nor I received any counselling during the course of my dad's illness or since he passed away.

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Section 7: Financial Assistance

33. I believe my dad may have received a payment to help buy me equipment for my ICT degree which commenced in September 2006. I believe this to have been a one-off payment and am not aware of the amount he received as this went directly to my dad - who did accompany me to Birmingham Bull Ring to buy a laptop, printer and the software needed.

Section 8: Other Issues

34. Following on from watching the ITV documentary – “In Cold Blood” it was mentioned that children born to an infected parent had their medical records categorised as “biohazard” and on foot of that, I put in a request for my records. Upon review of those notes I searched to see what tests were carried out on me to establish if my dad’s status had had an impact on my life right from birth. Some of the pages were illegible due to poor photocopying so I have been unable to clearly pinpoint what tests were performed.

35. Furthermore, since speaking with my mum, she remembers that I had a HIV test shortly after birth. She remembers they we were told after this had taken place and she cannot recall whether they gave any consent to this test. Again, as touched on above, elements of the records are illegible so unfortunately, I cannot establish what date this was performed.

Statement of Truth:

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

Dated the 21 day of 05 2021

Signed:

GRO-B