

Witness Name: D M Lever  
Statement No: WITN1762001  
Exhibits: 0  
Dated: July 2020

## INFECTED BLOOD INQUIRY

---

### FIRST WRITTEN STATEMENT OF DONNA MARIE LEVER

---

I, Donna Marie Lever, will say as follows:-

#### Section 1. Introduction

1. My name is Donna Marie Lever and I was born on **GRO-C** 1973. I live at **GRO-C**. I am married and have one daughter who is aged 4. I am employed by CAFCASS as a Social Worker.

2. **GRO-B**

3. I make this statement as an affected daughter of my late father, **GRO-B** **GRO-B** who was infected with HIV via contaminated blood products. He was born on **GRO-B** and passed away on **GRO-B** at the age of only 35.

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

## **Section 2. How Affected**

5. I refer to my [GRO-B]'s witness statement.

## **Section 3. Other Infections**

6. I refer to my [GRO-B]'s witness statement.

## **Section 4. Consent**

7. I refer to my [GRO-B]'s witness statement.

## **Section 5. Impact**

8. Growing up I had such a happy childhood with my wonderful father. He was a bit of a dreamer and had marvellous ideas about life and what he was going to do. I was read adventure stories about families who would sail around the world and settle in new places. I was led to believe that the world was my oyster and I could achieve anything if I read enough and worked hard.
9. My father wanted his children to be brought up in the countryside and in a bid for us to have the best experiences possible we upped and moved from [GRO-B] [GRO-B] to a small village in rural and leafy [GRO-B], where my family renovated a country cottage. My recollections of this time are the happiest I have from my childhood and Country life was idyllic. We had picnics by the river, went exploring, grew apples and damsons which we made into jam and pies, we had treasure hunts, went on country walks and made miniature gardens. My father was involved in all aspects of my school life as I recall. He was a quietly spoken but really funny man and he enjoyed my friends coming round for parties. I literally had the best childhood.

10. My father's friend was an RSPCA Inspector and he brought some ducks eggs to our house which my father put in an incubator in the garage. When the ducklings hatched and my mother went out to work, we sneaked the ducks into the bathroom, and they swam in her new corner bath. She would have gone mad had she ever found out.
11. My father was incredibly hands on and fully involved in my life which included assisting me with craft projects, organising bring a pet to school days and he was pivotal in both the helping with and planning of my homework.
12. My father was resolutely determined that I would not miss out on obtaining an education because his health had precluded him from obtaining the same. He took me to the mobile village library so that I could read about important historic events such as the reign of William the Conqueror. My father was incredibly politically minded, articulate and bright. He missed out on fulfilling his potential and having an amazing career. I often wonder what potential he could have realised if he had survived long enough to access the opportunities that come from the internet and distance learning.
13. I recall when I started secondary school the art teacher there remembered my Dad and spoke of his amazing creative talents and how he remembered visiting him at home once when he was absent from school.
14. Growing up I was aware that my father was not in the best of health at times and that he always walked with a slight limp. He was no longer able to go out to work but he was always busy and used to make things, do projects in the house and with us and "*tinker*" with cars. I know my parents struggled financially at times as Dad couldn't work, but we never went without clothes or opportunities and he would sometimes renovate and sell cars which allowed us treats like holidays.
15. I have memories of my mother and father having arguments at times, these sometimes centred on my mother reminding my father of his limitations to which his response was "*it is my life*". My father was never defined by his Haemophilia or his infections. When my father left school he worked at

**GRO-B** which would have been a risky job for a Haemophiliac; in fact had his employers known about his Haemophilia it is highly likely that he would have had to stop working there. He used to let me ride around on his back in the living room when he was on all fours and we would climb trees together. I think that it was to my father's credit that he never made me or my sister aware of any of his limitations or the pain he experienced at times.

16. I used to see his medical equipment such as the syringes and treatment in the house and on the days he had bleeds I could tell that he was in a lot of pain as he would be quieter and a little withdrawn. However, he mainly suffered in silence and never complained or let on how much pain he was in. I think he wanted to protect and prolong my childhood. Such was the normality of having his treatment and accessories around we used to ask for unused syringes at times as they made great water fight weapons on sunny days in the garden.

17. There did, however, come a point when things changed. I remember my father having a growth on his hip and having this looked at in hospital, which required an inpatient stay. My father had a cast fitted on his hip before he was discharged. On his return home, the cast seriously limited his ability to do things and I remember him taking himself off into his workshop and trying to remove it with his cutting tools. Around this time, I earwigged into conversations that were not meant for me and I soon picked up that my father was in a fairly poor state of health. Furthermore, because my father was never angry or moody, witnessing such behaviour from him was a wakeup call and made me realise that something was not quite right in regard to his developing health issues.

18. From this point on my father was in and out of hospital much more regularly and my mother was always at the hospital until there came a time when our old life became extremely disjointed was no longer tangible so when my Mum couldn't sustain the travel and caring for us at times we moved with her back to **GRO-B** and stayed in my Grandmother's small house there. I was enrolled into a local school and spent some of the time with my maternal

grandmother who helped care for me whilst my mother was at the hospital. I do not recall this as a happy time, I felt lost and missed my friends and the stability of life at home as a family. There were also times in the months preceding his death my sister and I were separated as my Grandmother couldn't care for us both and there was little room, so she went to stay in

GRO-B

19. I remember my father being sent home from the hospital, on one occasion, to our house in GRO-B. He was completely bed bound and his health had declined to the point where he was almost unrecognisable. My mother also acted oddly at this time, as if she was in "*some sort of a haze*". I recall lots of hushed conversations which my mother made on the telephone during this time but no explanation of what was happening was ever communicated to me.
20. I remember my mother struggled to cope and one day, her state of despair was so great that she just took herself off which resulted in my paternal grandmother arriving at our house, together with mutterings of disapproval that my mother had "*gone off and left me and sister*".
21. On another occasion I remember being left alone in the house with my father. He asked me to fetch him some medication (I can't remember what) but I experienced a sudden "*gut wrenching*" feeling that I should not do what he was asking so I side stepped the issue, I think, by saying that I could not find the tablets.
22. I also remember visiting my father in hospital on a few occasions and was acutely aware that his weight had plummeted and that he was really quiet and not his usual funny and enigmatic self. I have a letter he wrote to me from hospital and his handwriting is very large and from the text it is clear he struggled to write. On one occasion I was able to hold his hand and talk to him and on another visit, this was not possible. It was so sad and very confusing as to why we had to keep our distance and wear protective gloves and gowns without any understandable explanation, and it was almost like the person in the hospital bed was not my funny and spirited father anymore.

23. Around this time, I discovered (from earwigging) that my mother went to see a doctor in London in an attempt to find out some answers as to whether my father had "*this terrible disease* (HIV)". I remember being in the car one day and my mother pulling up at my paternal grandparents' house and going to speak with him. I overheard my mother saying, "*I think he has got it* GRO-B". There were lots of other hushed conversations at this time. I was none the wiser at this stage but I think my mother now believed that my father had HIV. However, I am now aware that she also questioned this belief as she felt that the hospital would not have discharged him back to her care with two children in the house if he was infected.

24. At this point I was still in GRO-B but my sister had gone to GRO-B GRO-B. I was often at my Grandmother's (nanna's) home whilst my Mum was at the hospital. Life was chaotic and plans could not be made. My idyllic country life, where my father had polished my school shoes on a Sunday evening, had it seemed long gone. We would grab tea and I would have to sit at peoples tables often to do my homework, I felt there was no routine or support and I felt very frightened and insecure.

25. I remember waking up, in my maternal grandparent's house, on the morning of GRO-B and hearing a telephone conversation between my grandfather and someone (my mother was ringing from the hospital) and being immediately aware that my father had passed away. I had not been expecting this; no one had warned me or told me that he only had weeks to live. I knew he was really poorly but he had been for some time and I did not realise that he would be taken so fast. I can't remember if it was my grandmother or my grandfather who came upstairs to tell me that my father had died. That was the second time that my world had fallen apart and I was faced with a new unrecognisable one. I would define that day as the end of my carefree childhood.

26. From that day on, and for at least a decade if not more, my mother became emotionally and physically unavailable to me at a time when I needed her most. I appreciate that it was horrific for my poor mother who was only aged

32 when she lost my father. However, from my point of view, I was a very lost and lonely child. I was bobbing about and floating around looking to replace what I had lost and yet never came close to doing so. I was angry and resentful and struggled to readjust to life without Dad.

27. My new life was almost unrecognisable. I remember being really unhappy at this time and my Mum clearly struggled to cope with the behaviours I displayed as part of my bereavement I was therefore sent, for a short time, to stay with my paternal grandparents, who only lived a short distance from our old house in GRO-B. I also returned to my old school. I enjoyed the routine and stability which was provided to me in abundance, I felt safe and cared for there but I was also acutely aware I was without my sibling and Mum, so always would be slightly different from my peers.

28. As a child I was always closer to my father because he was the one who was there in those formative years whereas my mother had to go out and work. Personality wise, I seemed to *"blend"* better with my father than my mother. We had shared interests and I felt emotionally more connected to him than I did to my mother. He was also the one person who supported my learning and I remember he helped me study and pass my eleven plus exam and I was awarded a full scholarship to attend a fee paying school in GRO-B, but I did not attend there based on the uncertainty of continuing financial assistance.

29. The next few weeks after his death, and for a long time after, were utterly traumatic. My mother could not cope and ended up being medicated. Initially we were all staying in one tiny cramped bedroom at my maternal grandmother's house in GRO-B. There was no routine, no bedtime structure and we were all crammed into one room. I only remember there being a single bed yet my mother, sister and I all slept in that room. The funeral arrangements were being made and that is when it came out, via the death certificate, that my father had pneumonia associated with AIDS. I guess that was when the *"bomb"* was dropped and I started hearing and finding out more about HIV. I was also aware that the undertakers could not do what they normally did and that my father's body had been put in a sealed

yellow bag. I was acutely aware that my father's death was not a "normal" one. I also saw that my uncles were beside themselves with grief. All of these things really impacted upon me as a child and that is when I started suffering from nightmares about him in a bag unable to breathe amongst others.

30. After the funeral we went back to family home in [GRO-B], and although my mother tried her hardest to cope, it soon became apparent that she was not going to manage so the decision was made to move, what was left of our family, back to [GRO-B]. I don't think my mother had ever truly settled or taken to country life and I was aware that she had discussed with my father, prior to his passing, the fact that she wanted to move back to [GRO-B]. In fairness to my mother, part of the reason for the move was that it would be closer to my father's hospital which was where both my parents were spending an inordinate amount of time.

31. I was very attached to our family home in [GRO-B] as it held such precious and wonderful memories of growing up there with my father. I was therefore very bitter and angry about the move back to [GRO-B]. I still have some diary entries I made at this time which read something along the lines of "*I can't believe she is making me move back to [GRO-B] I hate it there it stinks*".

32. I became an angry displaced child who was obviously dealing with all of the usual childhood things such as boyfriends, spots, greasy hair and other aspects of puberty at the same time as trying to process a significant trauma. It all became too much for me. All of my anger and emotions were directed as hate towards my mother. I meant it when I said to her "*I wish you were dead instead of him*".

33. I was at home a lot on my own at our home in [GRO-B] as my mother had to go out and earn a living. I was away from all of my friends in [GRO-B] and I felt very alone. My father was a Governor at my old school in [GRO-B] and I found out that a school assembly had taken place to commemorate his life. I desperately wanted to go back to [GRO-B].



34. Conversely, as time went on, my mother started to adjust to a new life in **GRO-B** and her friends all rallied around her and started to take her out. She was only in her 30s and it was not long before she was taken out for meals by potential suitors. Each one of those men represented a poisoned dart in my head and my heart and I reacted to each and every one in a very emotional angry teenage way.
35. I did not cope very well with my mother's decision to move on with her life. I started to slam doors and swear at her a lot which often culminated in physical fights between us. I then started to run away as I wanted to prove to her that I was important and that she loved me. I used to think "*I will make her worry about me; she will think I am dead*".
36. I remember on one occasion being in the car with my mother and my sister and was led to believe that I was being taken to a children's home. I jumped out of the moving car on route and ran away. I basically went from the girl who had her school shoes polished for her on a Sunday evening, did her homework and was almost top of the class academically to demonstrating chaotic behaviour which included jumping out of cars, spitting, swearing and running away. Idyllic early family life had been transformed into horrific teenage years. I was mad at my Mother and the world and unable to process the loss of my father.
37. It was at this point that my paternal grandparent's house became a safe haven for me. Routine and predictability were the key features of this household; I knew what I was having for tea based on which day of the week it was. It was just what I needed. I used to go on a Sunday and spend a lovely day with them and then dread returning to **GRO-B** for school on the Monday.
38. It was in the midst of one of the horrific arguments between my mother and me that she decided that she could no longer cope with my behaviour and took me to live with my paternal grandparents for the foreseeable future.

They were happy to help in whatever way they could and were not going to turn me away.

39. I remember my grandmother and me going to my old secondary school and I recall the conversation in which she told the head teacher that I would be returning as "*a very different girl*". I was not that happy and healthy child who left; I was unhappy and pale. It was good to see my old friends and I got to go to the teenage discos in the town but I was "*always different*" to everyone else as I did not have a father and I lived with my grandparents. Thirteen year old teenagers never want to be different. However, my grandparents did the most amazing job and managed to calm my behaviour. I recall my grandmother telephoned a Social Worker on one occasion as she was a bit concerned about me which led to a visit from a nice middle aged chap who spoke to me alone and decided that I was ok and so the involvement was short lived.
40. My sister used to come and visit me at our paternal grandparents' house and I used to get really upset when she left and I felt guilty about her having to return to GRO-B on her own. During the Summer holidays before I was due to commence Year 10, my mother told me that I had to make a decision as to whether I was going to stay in GRO-B or whether I wanted to come back to GRO-B; she needed to know as she would have to purchase the school uniform for me. The school I had previously attended in GRO-B was merging with a school close to where my mother lived which would mean that I would know some of the children there from my old primary school.
41. It was a difficult decision but I decided to move back to GRO-B and live with my mother and my sister and I completed both Years 10 and 11 at the new merged school.
42. In some ways going back to GRO-B at this time presented me with a chance to be free of the past. I could effectively be that "*anonymous child*". I knew that I was different as I only had one parent and our lives were chaotic but then this was also how a lot of other kids lived.

43. However, sadly the position between my mother and me was still the same; we still had our arguments and some difficult times. I also started to self harm at this time, by running into my bedroom wall and hitting my head extremely hard which caused pain and brought instant relief. I would then drop onto the bed. On dark days, I thought about ending my life but I never had any real intent to go through with it. I would go the bathroom cupboard and get out all of the tablets and lay them out on the bed. I would then just look at them. I would also think about writing a note and what it would say but on reflection I can see it was all just reactive and a cry for help. I was still hurting, and I did not know how to heal myself.
44. Looking back, I now know that what I felt and experienced during those years was depression but of course as a teenager you don't have the knowledge or maturity to label it as such.
45. In terms of the educational impact on me, I counted five school moves during my formative years. On one occasion, everyone had chosen their options whilst I had been moving schools, so I had missed the selection procedure and was hurried into choosing them on the first day at my new school. Different curriculums were taught at the different schools which meant that I was ahead in some subjects but behind in others. I managed to catch up in most of my subjects due to the fact that I was bright and the groundwork which my father had put in when I was younger meant I was a keen learner. However, science was always difficult; when you miss Periodic Tables there is no hope for you! I also struggled with maths, particularly with fractions, despite the fact that I was in the top set for this subject. I was moved down from the top set where I had always been throughout school in Maths and science as I struggled to keep up, my grades went from A to B and C initially.
46. With all due respect to my mother, education or the valuing of the same, was not one of her strong points. This made things difficult because I had no guidance or assistance with my homework, projects or future Education and

career options. I remember subsequently being really keen to help my sister with her school work because I did not want her to struggle like I had.

47. In terms of the impact upon my childhood and teenage years, in essence, it ended there in October 1985 because at that point I became a carer for my sister whilst my mother was having to work full time to maintain our home and needs. I remember having to go to the end of the road each day after school to cross my sister over the main road, take her home and cook her tea which meant that I would miss out on any after school clubs, such as netball.

48. Two things happened which helped me in terms of my healing and recovery. Firstly, I got a boyfriend who became my first love. I spent a lot of time with his "normal" family who took me under their wing and I had a very close relationship with his mother which was lovely. Secondly, I threw myself into drama and ended up pursuing this beyond my school years. I knew that my father would not have allowed me to pursue this route as he valued academia too much whereas my mother had no such concerns. I ran off to drama school where I found that I was no different to anyone else; in fact, I was pretty normal compared to my new drama mates. I found my freedom, escapism and an outlet for my emotions in this environment.

49. As each year passed, I became increasingly emotionally mature and have developed improved coping strategies which have allowed and afforded me the ability to adjust more to the loss of my father and also to the "*loss of the family unit*".

50. In terms of disclosure, my Year 10 peers just assumed that my parents were divorced and that was why my father was not around. I never felt inclined to rectify their incorrect assumptions. It was bad enough coming home from school and seeing AIDS campaigns, utilising tombstones, on the television and I could tell you exactly where I was and what I was doing from the age of 13 to adulthood, when someone told an AIDS joke. If anyone found out that my father had died, I would tell them that he died from a blood disorder. However, people often assumed he had cancer which meant that I did not

have to say anything. It was a long time before I could tell anyone that my father had died of AIDS.

51. When the Inquiry started, I had supervision with my manager, during which he asked how best to help and support me during this time. This was the first time in my life that I was able to say confidently that my father died of AIDS. My manager said that he had not told anyone else in the office but I assured him that it was fine and he could tell everyone. It has taken the Inquiry and the fact that I was then part of a recognised group, courage and 35 years for me to confidently walk into court for my day job with my ribbon on. Today I would happily tell anyone that my father died from HIV. The truth has been hidden for far too long, the hysteria no longer attaches itself to HIV and people's attitudes are slowly changing.

#### **Section 6. Treatment/care/support**

52. I refer to my GRO-B's witness statement.

53. I remember visiting the hospital and being confused and frightened because the medical staff made my mother and me put protective aprons and gloves on before they allowed us to see my father. I could see how anxious this made my mother and at no point did anyone tell us why they were making us wear protective clothing.

54. I have never been offered any counselling or psychological assistance in consequence of my father's infection or subsequent passing.

55. A chance discussion with a psychotherapist I met when I was working at a special needs drama workshop led to me having some psychotherapy sessions with her. This mainly focused on my mother's new relationship at the time and my coming to terms with the same. She gave me a journal and in this I wrote down how I was feeling and also things about my father. I found the whole process quite cathartic and I still have the journal in my loft.

## **Section 7. Financial Assistance**

56. I refer to my GRO-B's witness statement.

57. I remember receiving some money when I was aged 18 and that my sister received a little more because she was younger than me. I used the money to go interrailing around Europe.

## **Section 8. Other Issues**

58. I feel grateful that my story is not as tragic as some of those that I have heard. I only lost one parent and I did not end up in the care system. I did not have to witness my father battling with his health for years or be subjected to the cruelty of stigma.

59. I would like to be able to access the whole truth about what happened, and I think this should be published for everyone to see. I think those who have suffered need answers and to have at least one less fight in their lives, which will hopefully be the case following the conclusion of this Inquiry. I also believe that these people need to be given the opportunity, and for some this means the financial freedom, to be able to live the rest of their lives as they should have been able to live all of their lives.

60. In terms of the campaigning I would describe myself as being "*on the periphery*" which I think has been necessary in order to preserve my mental health. I have witnessed people in similar situations to me, who have become heavily involved in campaigning and gone on to develop enduring mental health difficulties.

61. However, in some ways it has been cathartic going to the Inquiry and hearing people's stories but in other ways it has been more of a "*Pandora's Box*" situation and I think "*goodness I could have ended up like that*". After spending years being an angry and lost young person I wanted to create my own happy bubble.

62. I delayed having my first and only child until I was aged 41 which was mainly due to what happened to my father; the thought of having a child who could have Haemophilia reignited in me the fear of HIV and the resultant suffering this entailed. When I contemplated assisted conception to ensure that I was carrying a girl, I was emotionally overwhelmed at having to deal with health professionals at the same hospital which my father had been treated in.

63. It would be easier to talk about which parts of my life have not been impacted upon by what happened to my father as the thread runs thorough nearly every aspect of my life and has been the driving force behind most of the decisions which I have made.

64. My emotional wellbeing has been influenced by my life experiences and how I function in the world. I am a bit focused on routines and ensuring my own daughter has set meals and support with her learning, as I am aware of how the absence of this made me feel insecure in my later childhood years. My own childhood experiences meant I was drawn to social work and have had a strong desire to work with children and families. I did not end up going to university until I was a mature student because I did not feel able to leave home alongside my peers at the time, as I didn't have the financial or emotional security that was required to venture far from home at the age of 18 or 19. I also did not have that stable or secure home to return to each semester nor were my parents able to drop me off in the car at the start of each term. I often wonder what path my life could have taken if we weren't affected by this issue as when I eventually did attend university I discovered I enjoyed the module of family law, and was good at this and perhaps would have been able to pursue this if circumstances had allowed.

### Anonymity

65. I do not want to apply for anonymity and I am happy to provide oral evidence if this would assist the Inquiry. Giving evidence is *"part and parcel"* of my day job.

**Statement of Truth**

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

Signed....

**GRO-C**

Dated.....18/08/2020