

Witness Name: Luke Burnett

Statement No: WITN6419001

Exhibits: WITN6419002

Dated: August 2021

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF LUKE BURNETT

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I, Luke Burnett, will say as follows:-

#### Section 1. Introduction

1. My name is Luke Burnett. I was born on GRO-C 1984 and I live at GRO-C  
GRO-C West Sussex GRO-C
2. My father, Kim Leslie Burnett (born on GRO-C 1958), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died on 20<sup>th</sup> April 2003, aged 44. I refer to Exhibit WITN6419002, being a copy of my father's death certificate.
3. This witness statement has been prepared without the benefit of access to my father's medical records.

## **Section 2. How Affected**

4. My father (Dad) had severe Haemophilia A. GRO-C
- GRO-C My Uncle went to a local mainstream school and Dad boarded at the Lord Major Treloar College at Alton in Hampshire. He was under the care of the Haemophilia Centre there whilst at school and otherwise under the care of the Southampton Comprehensive Care Centre at Southampton General Hospital.
5. Dad was treated with Factor VIII (FVIII) concentrate self-administered at home. I do not know how, when or where Dad was informed that he had been infected with the viruses. I wasn't told myself until after I had left home (and living with a friend) when I was 16 or 17 years old. My mother's sister (my Aunt) married my father's brother (my Uncle). I was told that my father was infected with HIV by a doctor or counsellor (I am uncertain of her capacity) who had come to my Aunt and Uncle's home to find out what I already knew and to speak to me about my father's health issues. I was told that my father was also infected with HCV, but that infection seemed to be secondary and of less importance to the HIV infection. I was told that my father was infected through contaminated blood products. I remember my Aunt, in tears, saying 'you need to understand that this hasn't happened because your Dad has been sleeping with other women (or men)'. She didn't want my father to be judged or for me to think anything wrong of him. In fact, the thought hadn't even occurred to me as my head was in a different place. It was a lot to take in and process.
6. Looking back there may have been a handful of times where "The adults" would mention my dad's health but in a covertly manner, mainly talking about Haemophilia but actually meaning HIV. My grandfather or any other family members wouldn't speak of my dad's illness or acknowledge it at all whilst he was alive publicly. It was most definitely a close kept secret.

7. My father's HIV infection was always kept hidden from me because of the fear and stigma of AIDS. I remember at the age of 14 or 15 attending one of my Dad's haemophilia appointments with him and his reaction when the doctor mentioned HIV in my presence. Dad bristled and brushed it away and the doctor then continued but confined his comments to Dad's haemophilia. Dad and I had a shared interest in IT, and I could access Dad's emails without his knowledge, the emails included details about his haemophilia, and even some touched on HIV and other references though I didn't tell any family members that I had read them. I don't think I absorbed what I was reading. I knew my father had Haemophilia but perhaps assumed the HIV information was just generally speaking rather than directed for him. I recall the emails but not the content.
8. I do not know what information and/or advice was ever given to my parents to manage the infections. They were, I know, aware of the risk of unintentionally spreading the infection(s). I remember, in my teens, picking up and using my father's razor. Never was I more shouted at. Dad probably didn't remember the incident for long afterwards, but I remember it vividly. I couldn't understand why it was such a 'big deal'. I thought his anger was directed personally at me, but I can see now that he was afraid for me.
9. I have other childhood memories that now make more sense to me. I remember my parents avidly following the Mark Fowler HIV storyline on EastEnders, this was 1991, and being told to be quiet when they were watching it. They weren't ordinarily soap opera fans; well my dad definitely wasn't. They would sit silently listening to how the story unfolded but not make a big deal afterwards in my presence. I remember my mother taking *me* for two or three, what were described as 'routine', blood tests without any apparent reason as they weren't routine at all. This was at Lordshill Heath Centre in Southampton. I even remember my maternal grandmother questioning my mother as to why I needed a blood test and my mother swerving the question. I do not think my maternal

grandparents (my mother's parents) were told that my father was infected with HIV until sometime later. It was all 'hush hush'.

10. Unlike other parents of friends that I saw curled up watching TV on the sofa together, I never saw my parents interacting and being tactile. Dad being infected must have had a profound impact on their relationship. I was an only child and I remember playfully asking my parents if I could have a brother or sister. Their reaction and response were very awkward. Mum tried to laugh it off and Dad wouldn't immediately answer and then said 'you are enough' in a playful manner to avoid me questioning them even more. Given their circumstances I can understand why my parents kept Dad's infections from me, but I cannot help thinking that I might have coped with life a little better during what turned out to be a very difficult period of my life and something I truly am affected by to this day.

### **Section 3. Other Infections**

11. I am not aware of any infection other than HIV and HCV.

### **Section 4. Consent**

12. I think it likely that Dad was treated and tested without his knowledge and consent.

### **Section 5. Impact of the Infection**

13. As I was unaware that my father had been co-infected, I didn't take too much notice of what was going on. He had to take 10 to 15 tablets daily and some of

them were as big as two pence coins. I remember him self-injecting a product (I now understand to be Interferon) into his stomach and wincing as he did so. It affected him physically and mentally. It made him depressed, short tempered and moody. My parents had a lot of arguments. After one particular argument with my mother, I watched my father from my bedroom window go out into the garden to light and smoke a cigarette. He had up until that point given up smoking for something close to two years.

14. Dad being infected and the side effects of his Interferon treatment had a catastrophic impact on my life. It resulted in my parents splitting up and the start of what turned out to be a pretty crap time all round. I was 16 years old. My mother announced she was leaving (moving out), **GRO-C**

**GRO-C** I was at that time heading adjusting from a boy to becoming a man and heading off to college, and my father (unbeknown to me) was dying. I did not understand or know how to deal with any of it – My family was torn apart and there was nothing anyone could do to correct it. Dad and I had a lot in common to include our love of technology and electronics, but I was a rebellious teenager and Dad was short tempered and moody and we clashed. My mother leaving us and walking away from our family didn't help matters at all, I believe my father gave up hope and almost didn't feel like he was worthy of living. **GRO-D**

**GRO-D**

**GRO-D**

**GRO-D**

**GRO-D** I regret it now, but I moved out eventually too due to conflict with my father, I lived with a friend renting a flat. I really felt like I had no choice, my mother had left to start a new life as my dad's entire life was falling apart. I was confused, unable to come to terms everything, all at once I had to deal with an affair, my mother distancing herself, HIV and AIDS, and my father dying. It was so much to take in. Dad was left on his own and I cannot help thinking that led to a deterioration in his health. He must have wondered what he had to live for, and, what was the point. My heart aches with

the guilt I feel inside for not being the level headed person I am today and being able to help him during his biggest struggle.

15. Dad knew that he was in a bad way. I remember him in hospital on one occasion and he seemed worried. I didn't want him to worry and tried to distract him by talking to him about us going to see a new Star Wars movie they were talking about making. We always watched the Star Wars films together. It was something we both enjoyed. He grabbed my hand and he said to me 'I won't be here for that'. I said 'of course you will'. It was the first time he spoke to me of his fears.

16. We were formerly a very close-knit family. As stated, my parents' siblings were married to one another and we spent a lot of time together to include holidays to Spain and in 1993 my parents and I went with the whole family on holiday to Disney World in Florida. There were 11 of us to include my cousins and grandparents. Each year, one family members household host Christmas, we would all attend and rotate this throughout my childhood, right up until my parents split. It would be a fun and loving time – something I truly miss.

17. Dad lost a lot of weight and was jaundiced before his death. I had difficulty in believing or accepting that anything bad would happen to my Dad. I was a teenager and whilst I checked in with Dad once in a while, my face to face visits with him were sporadic. At one point in time I hadn't seen Dad for something approaching a couple of months when my Uncle got hold of me to say 'you need to see him'. It wasn't a suggestion. The message was clear 'you *need* to see him'.

18. I went home to visit Dad and I knocked at the door. I knew Dad was in, as his car was on the driveway as usual, but I stood there on the doorstep for what felt like 15 minutes. In reality, it was definitely a good five minutes just waiting for Dad to answer the door (to a modest/ordinary sized house). You can see the stairs through the window to the side of the front door and eventually I saw

Dad appear and make his way slowly down the stairs to open the door. He struggled to open the door. He then struggled to get back up the stairs and crawl back into his bed. The deterioration in Dad over that two-month period since I last saw him was striking and I was scared by his appearance. He was so thin that I could see his skeletal bone structure. He was wearing shorts and a vest top, and I could see the outline of his skull, jawline and collar bones protruding through his skin. It is one of my last memories and it is a horrible one. Dad was formerly a good looking, strong man, over 6ft in height. He ordinarily dressed well and carried himself well.

19. I also still remember subsequently visiting my father in hospital before he died and not recognising him. He looked like a skeleton and nothing at all like his former self. This is still my final memory of him, being able to see almost every single bone in his body as he battled as hard as he could to overcome something that could never be cured.

20. Because of my father's death I have battled with depression, self-confidence, work life, relationships, and other trauma due to the nature of the circumstances he experienced as well as trying my best to come to terms with my father dying so young at 44 years old. From the age of 18 years old I lost my father in my life due to HIV and HCV and that's something that I have to deal with on a day-to-day basis.

21. I had a strong bond with my father, we related on technology and computing and this was taken away from me and my family. My grandparents had to bury their own son – something no parent should ever have to do. This overall, caused problems not only for me but my entire family and changed the way we are today.

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

22. Dad was given treatment to clear HCV that probably did him more harm than good. I do not know if he was offered any counselling.

23. I wasn't offered any counselling and haven't been contacted by any organisation since Dad's death. I have battled with depression and have a tendency to flare up and be short tempered when upset. I get frustrated at small things and can only relate back to bad times in my life when something goes wrong in my present, day to day life. I do not have the best of relationships with my mother, we are very distant, because she left when my Dad and I were at our most vulnerable and no-one told me what was going on. She has never once apologized for having an affair, leaving him to fight for himself, or ever apologised to me for leaving our family home and changing our lives. For years I was in and out of jobs (I walked out of a couple). Having studied IT at College, I lost my way for a very long time. I worked as a bar manager whilst my friends were on substantial salaries in IT. Unlike my friends I no longer have a father to call on in a crisis. I haven't had that for getting on for 20 years. I do not remember much about my late teens and early twenties. I couldn't tell you what I did on my 18<sup>th</sup> and 21<sup>st</sup> birthdays. A lot of my memory is, I think, just blocked out.

24. I always felt different and life has been difficult, but I am in a happier place now. I have a happy relationship with my partner of two years. I found myself in Hampshire relatively recently as I enjoy running and I was there doing a half marathon there. I didn't know it until the route was announced at the start of the race, but our route took us passed Treloars College. The realisation of where I was, made me uneasy and a shiver ran down my body. Dad is never far from my thoughts.



## **Section 7. Financial Assistance**

25. I do not know whether Dad had any help and support from the Skipton Fund. I know that he had support from the MacFarlane Trust (MFT).

## **Anonymity**

26. I do not seek anonymity and I understand that this Statement will be disclosed for publication to the Inquiry.

## **Statement of Truth**

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

Signed.....

**GRO-C**

Dated.....**30.09.2021**.....