Witness Name: Colin Midgeley
Statement No: WITN3968001
Exhibits: 0
Dated: September 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF COLIN MIDGELEY

I, Colin Midgeley, will say as follows:-

Section 1. Introduction

1. My name is Colin Midgeley. I was born on GRO-C 1974 and I live at GRO-C GRO-C Kent GRO-C

2. My father, Dennis John Midgeley (born on GRO-C 1947) was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died on 27th January 2018, aged 70.

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

Section 2. How Affected

4. My father had mild Haemophilia A. He was eldest of six siblings. He was one of three brothers, GRO-C

5. My father was very careful with himself and rarely had a bleed. It was even rarer for him to need treatment although I remember him having Cryoprecipitate in hospital ahead of a tooth extraction when I was very small. He was absolutely fine then with no problems at all.

6. I am uncertain as to the name of the Haemophilia Centre with responsibility for my father's care but he attended at Lewisham Hospital in 1983 or 1984 for what I believe was a routine blood test. Whilst there, the clinicians noticed that he had a mark and bruise on his thumb. My father initially refused any treatment for the bleed in his thumb because he didn't believe that he necessarily needed it.

7. He was not given any information or advice about the risk of infection prior to treatment. He was a family man and he would not have had it had he been aware of any risk of infection. He was given Factor VIII (FVIII) concentrate at Lewisham, described to him as a new/better treatment. He was convinced to have it against his better judgment. It was the one and only occasion he was treated with FVIII concentrate and that particular treatment was responsible for infecting him with HIV and HCV. Many years later, some time in the 1990s I believe, my father was part of a group action in Philadelphia and the manufacturers of the FVIII concentrate settled his claim out of Court. I do not know how much he received.

8. I do not think my father was told that he had HIV until in or around 1987. They knew my father had HIV for a long time before that. They were monitoring our whole family before my father was even told. I have a clear memory of going to the doctors with a sore throat and having to have a blood test.

9. My father took a phone call informing him that he had HIV. He was informed that he was infected with HCV by letter in 1992 or 1993.

10. No information or advice was given to my father to assist him to understand or manage his infections. He was very much in tune with his health and, being a

Haemophiliac, he watched himself a lot more than most other people. The manner in which my father was informed of his infections was terrible. When he was told that he had HIV, he was told that he probably had just three years to live. He should have been told that he was infected much sooner at a face to face appointment. My father didn't need the FVIII treatment in any event. He was given FVIII on just one occasion and that was the only FVIII concentrate he had until many years later when he had his gallbladder removed.

11. The way my father was treated, as worthless and disposable, was disgusting. The way that my family was treated was disgusting. They waited a totally unacceptable period of time before informing my father that he had been infected and in doing so they put our entire family at risk. Our parents were still young at the time GRO-C Once my father knew he had been infected, he shunned his children, no longer helping if we hurt ourselves and sending us to our mother instead. He stopped playing football with us. I found out what had happened to my father when I was 22 years old and the change in my father I had seen years before then made sense to me.

12. Up until then my father had protected us, his children, from the truth of his reality. I even remember my father telling us that he had won the football pools after the conclusion of the HIV litigation in 1991 to explain why we had come into money.

Section 3. Other Infections

13. In or around 2010 my father received a letter asking if he wanted to know if he had been exposed to vCJD. I remember my father told me that he already had a lot to deal with and didn't want to know.

14. When my father was at Medway Hospital in 2011, his medical notes were left open in plain view of anyone and everyone passing and I could see my father

was classified as high risk of vCJD. The lack of dignity and respect that my father received at that hospital was unbelievable.

Section 4. Consent

15. My father was tested without his knowledge, consent and without being provided with adequate or full information. My father was never even given any inkling that there was something wrong with the FVIII product he was given until he was told that he had been tested for HIV and the result was positive. .

16. I believe he was also tested for the purposes of research. I am confident that I was tested for the purposes of research as were my siblings. We had blood tests for common illnesses. None of us questioned the need for blood tests. The doctors were thought of as Gods by us and we were treated as guinea pigs by him.

Section 5. Impact of the Infection

17. My father (Dad) had a whole raft of health issues to contend with through being infected with the two viruses. By the time my father was told that he had HCV it had already had a damaging effect on his body. The HCV infection damaged my father's liver and he developed problems with his gallbladder. He was riddled with pain with his gallbladder night after night and it was horrendous. He needed to have his gallbladder removed and the hospital left to the very last minute before the operation took place. I remember the surgeon saying that had Dad not come in for the operation when he did, he wouldn't have survived. I had no idea that Dad was infected back then. I remember a young nurse taking me to see my Dad on my first visit. She knew that my Dad was infected with HIV and HCV. She was clearly very nervous but was laughing as she showed us the side room where Dad was and I had no idea then as to why.

18. Dad had a course of Interferon and Ribavirin around the same sort of time as having his gallbladder removed (in the early to mid 1990s). It would have been a relatively a short time after being informed he had HCV and before I knew about it. Whilst on the treatment he became very insular and short tempered. My Dad was a positive and sociable man but he changed whilst on the treatment. It made him miserable and snappy with a short fuse. Mum struggled to keep him calm. He lacked energy and he was always sleeping, He was nauseas and lost his appetite. He struggled to work but pushed himself to keep working. My Dad would always go to work and he worked right up until the day he was physically unable to do so anymore. The HCV clearing treatment was unsuccessful.

19. My Dad had a second attempt at clearing HCV with a different mix of Interferon and Ribavirin in the late 1990s. This too was unsuccessful and the side effects were even worse than the first attempt. Dad was physically sick, vomiting in the toilet. He was so tired and lethargic that if he so much as sat down he would literally fall asleep. That tiredness stayed with him for the rest of his life.

19. Dad was sent for a liver fibro scan and then a CT scan of his whole body. After finding nodules in Dad's bladder and further investigations, he was diagnosed with transitional cell carcinoma (bladder cancer). They must have known that something was wrong to send him for the CT scan. My Dad hadn't had any symptoms. As he was on medication for HIV, he was unable to go through chemotherapy. Instead they treated him with something called Mitomycin-C given intravenously, directly into Dad's bladder through a tube inserted into his penis. He had one tube in and one tube coming out and he had to lie still for 30 minutes whilst the treatment went in, sat in his bladder and came back out again. He was treated at St George's Hospital in London.

20. I remember that after one course of the Mitomycin-C treatment Dad succumbed to a UTI and was unable to even walk. The memory of the distress my father experienced and how he was treated that day is a vivid one for me. My mum phoned me and I could tell immediately that she was very

scared. When I arrived at their house, I had to carry my Dad to the toilet. After I had managed to get him back from the toilet, I called an ambulance. I explained what was going on with Dad, that he was a cancer patient and that he was very well. As soon as I also told them that he was infected with HIV and HCV they refused to come out to him. It was only after my third call that they agreed to come out and not before I also agreed to contact the Haematology Department at Lewisham Hospital (even though they needed to take Dad to the Medway Hospital instead).

21. It was horrendous, the medics arrived double gloved and suited up in full PPE. They reversed the ambulance up on to our front lawn and as close to our front door as they could get. It was as though they didn't want to be there and they didn't want people to see what was going on. My Dad had no idea what was going on. He didn't even know what day of the week it was. He was taken into a side room at Medway Hospital A&E. He had no control over his bladder and was wetting himself. He needed to be looked after but nobody would help him. He was ignored. The ancillary staff wouldn't even come into his room and help him change. They just left his clothes on the end of his bed and told my mum she had to change him. She had arthritis and really struggled. There was a delay in waiting for Dad to be admitted on to a ward. I asked why and they told me that Dad had to have his own side room on the ward because of his infections.

22. This is just one example of many that Dad was discriminated against and stigmatised by the medical profession. My Dad discharged himself from Medway Hospital as soon as he was able to. He was very unwell and he had ulcers all around him mouth. His immune system was completely shot. He always felt more comfortable at Lewisham Hospital where he had a rapport with the staff and could trust them to look after him.

23. My Dad went through such a lot. After being told that they had successfully treated his bladder cancer, my Dad was told that he had cirrhosis of the liver. He was then given the terrible news that he had hepatocellular carcinoma (liver cancer). He then had to undergo surgery to remove the cancer, losing a

good proportion of his liver in the process. We sat back and watched and waited and the cancer came back with a vengeance. The only option was to have a liver transplant. In 2014 my father had a successful liver transplant.

24. When we got the call that my Dad had a liver donor, the transformation of hope in him was amazing. He walked out to the ambulance and he looked in such good health that all the clinicians were pleasantly shocked. The transplant took place at Kings College Hospital (KCH) and it was the worst night of my life then. I was up all that same night with my mum, phoning constantly for updates. We had to do all the chasing as they didn't keep us as informed as we would have liked.

25. The next day we insisted in coming up to see him notwithstanding being informed that they had tried to wake him up without success. At hospital, we learned that there had been complications during Dad's surgery and because of a massive bleed in his spleen they couldn't stop they had to remove it. Dad was moved into the ICU after the operation. It was so hard to see him on his knees. He was always so strong. He was gagging on the tubes and he was in pain. The staff there was good to Dad but he was very unwell. He made a full recovery from that transplant but he had to go back in to hospital several times due to resulting complications like fluid on the lung and to have a drain put in. Dad and I journeyed to and from KCH on a weekly basis at first. It then dropped to fortnightly, then monthly before having to attend every six months. Dad had a life of hospitals. All he ever did was go in and out of the hospital. He bore it bravely.

26. Sadly, after the liver transplant the bladder cancer came back and they couldn't control it. They tried the same treatment method they used the first time round but it was unsuccessful. The only thing they could do was to take away his bladder completely. He went into St George's Hospital as he wouldn't go to a local hospital. His experience at Medway Hospital deeply affected him. He was so scared of people finding out about his infections. We went down on the train and bounced around on the tube.

27. They removed Dad's bladder in or around 2015/16 and Dad being Dad he bounced back again. He had the operation and as soon as he was awake he was out of bed. He always determined to get better and look after everyone else. I still thought Dad was invincible then too.

28. Dad tried to get on with his life after the operation but it took him ages to recover and he had to wash himself very carefully. The embarrassment of carrying the bag around was absolutely horrendous. He used to have to connect the stoma up to a bag at the side of the bed at night. It used to leak sometimes but he never showed us the wound/entry point of the bag. He didn't even show Mum for a long time. He was so disturbed and embarrassed by the sight of it himself. Dad was a 'hands on'/pragmatic sort of guy. He used to say 'What the eye doesn't see, the heart won't grieve over'. He shielded us even then.

29. Dad was very independent and used to go for check ups at the hospital on his own. We thought he was doing alright and we thought they had got all the liver cancer but signs of liver damage were re-emerging from in or around 2017. I remember that I was replacing the driveway at his house and he helped me just as much as he could. About two or three weeks later he phoned me out of the blue and told me that he and Mum were moving. He said that a lovely one bedroom retirement place had become available and that he and mum were both moving there. It seemed to me to be a rather quick decision to make, unusually so. The place they had was lovely enough but Dad pushed himself through to completing the move. I should have asked more questions and pressed for more answers but he said everything was aright. I kept asking him if everything was okay throughout the sale and the move and he said yes everything was okay. I was working at the time and he wanted me to take time off work once they moved in so they could do some work on the place. He tried his hardest to do this place up himself once he had the keys but he really did struggle. He had no energy no matter how hard he tried. Dad didn't tell us that he was terminally ill. He tried to protect his family. His first thought was always us.

30. My parents went on holiday around Christmas time 2017 for their 50th anniversary and they wanted to make it special. Dad used to love the Isle of Wight and they went there. He wasn't well before they went over there but they still went. He looked after my mum and that's where she wanted to go too. He idolised her. They had a wonderful relationship. My parents returned on 29th December and my Dad was beyond poorly. They got stuck in terrible traffic on the motorway on the way back and from there he took a very serious turn and never recovered. He couldn't control his bowels anymore. He took a massive dive downwards. He couldn't do anything for himself anymore. He didn't want to eat, he had to crawl on his hands and knees because he could no longer walk and he had turned yellow in colour. He could no longer cope and he told my Mum that he was scared. That was so unlike him and my Mum called an ambulance. I met them both at Medway Hospital A&E where Dad had been treated so badly previously but he didn't want me there when he and Mum spoke to the doctor. Mum went in with him GRO-C GRO-C and he was admitted on to a ward. He had a lot of doctors and specialists dealing with him, all trying to find the problem. They were even in contact with KCH.

31. The doctor dealing with him told us that Dad's case was very complex. She had never dealt with anyone whose medical history/folder was so big. They couldn't do a CT scan with contrast because his liver wasn't able to deal with it. He deteriorated further and had to go into the ICU. They still didn't know what was wrong with him and he went from there to the HDU. They had to sedate him and put him to sleep because his breathing had got so bad and the oxygen levels in his blood were dropping. The risk was that he may never wake up again and they had no option but to transport him to KCH in London.

32. At KCH he was in the liver ICU. When we visited him he looked horrendous. He had ballooned up as they had to give him fluids. They did scans but they were a risk alone because of the effect they would have on his other vital organs. He was asleep and knew nothing of it. They tried to wake him up a

few times and stopped all his treatments to do so. He wouldn't wake up. There was nothing and he was on life support.

33. I cannot begin to describe how incredibly distressing and traumatic it was for all of us. We were summoned to the hospital on the Friday evening. We met with the consultant in the side room and saw the scans of my father's liver. He told us that he had never seen a liver transform so quickly. Three quarters of his liver had become cancerous and if he were to survive which was unlikely he would have massive problems. We were also told that any treatment available was unlikely to be successful. In short, there was nothing more that they could do and Dad was being kept alive by machines. They wanted us to agree to turn the machines off and we did it together as a family. We had time to talk about it between ourselves but we knew that Dad wouldn't want to suffer. We knew he would put up a good fight and we agreed if he did survive he would have wasted away and he wouldn't be able to walk. He would have been bound to a wheelchair. We were left in the impossible but very real position that it was up to us to kill our Dad and the knowledge that I was part of that lives in me every day.

34. Dad's Death Certificate lists as multiple organ failure, liver infiltration with metastatic adenocarcinoma, transitional cell carcinoma of the bladder, liver transplant (2014) for hepatocellular carcinoma secondary to HCV cirrhosis, HIV and Haemophilia A.

35. In terms of stigma, as previously stated, Dad was treated poorly by certain members of the medical profession. Dad was also last in the queue when it came to dental work. I remember taking Dad to St George's Hospital and he had to have a pipe down the throat. Afterwards, when he was coming around, they said that the equipment they used would now be thrown away.

36. There were always two sides to my Dad. He was a very private man on the one hand and he was also a very giving, sociable side to my Dad. He would give you his last penny if he could. There were only ever a few people very

close to him who knew of his status. People referred to HIV/AIDS as a dirty disease. Dad used to go to the pub to socialise and he couldn't talk to anyone about what he had. A couple of the friends that he did tell he lost contact with. They dropped him. I wasn't told the truth (by my Mum) until I was 22 years old. We were shielded from it but in retrospect I do remember comments from other people saying things like 'haemophiliacs have dirty blood'.

37. I remember telling a dinner lady at junior school that my Dad was a haemophiliac. The dinner lady pushed me away and told the rest of the kids not to play with me. I was then shunned from the rest of the kids and it set a precedent for the rest of my school life. It separated me and I didn't understand why. It wasn't until later on in life that I linked it.

38. The stigma was horrendous and Dad was terrified his status would get out into the community. When he went to some of his appointments some of the stories of the experience of others was horrendous. The adverts on TV were horrible and the effect that must have had on my Dad must have been just horrible for him. There were constant jokes about AIDS especially in schools. For Dad to sit and hear that sort of thing must have been horrendous for him. Mum and Dad held together and stayed together through it all. That's love.

39. Not even Dad's brothers (both infected with HCV) infected knew about Dad's diagnosis. No one at his work knew about his infections. He had to be so careful not to hurt himself there.

40. My dad stopped working about the age of 60 because his health deteriorated and he couldn't go on. It was miraculous that he continued for that long. He was only given three years to live and he couldn't plan for the future. He had a career as a site supervisor for a large wood company. There were lots of opportunities he was unable to take because of his infections. He couldn't better himself or increase his salary or way of living. He didn't know where he was going to be with his health from one day to the next. Mum and Dad

were not lavish and they used to get clothes for us from car boot sales. He was always living in fear that something was going to happen.

41. Dad used to go to group meetings with the MacFarlane Trust (MFT) and he would talk to the guys down there. They told him to make a claim for disability allowance. He had never had benefits before and I believe that he would have continued to work had he not been infected.

42. I lost my wife very suddenly in February 2017, the year before Dad's death. Loosing the two closest people in my life in such a short space of time is one of the worst things a person can go through. I have been deeply affected by the manner in which I lost my father. I suffer with anxiety and stress as well as a health anxiety disorder. I now have palpitations and panic attacks.

43. My Mum told me about Dad's infections. She needed to tell me and so she did. I didn't understand it. The guilt has stayed with me all these years that I didn't support him enough. Life went on. Mum told me not to tell anyone so I didn't.

44. I was always involved in Dad's medical care. I was his main contact if anything happened. Not being able to tell anyone that Dad had HIV, to keep it a massive secret and not even breathe a single word was a very hard path to walk. My Dad was a very social character but in effect had a double life only we knew about it. In turn, he wanted to protect us, his family and pushed us away as a result.

45. I have visited my doctor many times since my father's death. I have been taken by ambulance to A&E on two occasions since the Covid19 outbreak. My doctor believes that what I went through with Dad and all the pressure with losing both wife and father set off my health anxiety disorder.

Section 6. Treatment/care/support

46. My father struggled to get the treatment, care and support he needed because of his infected status. He had a near fatal delay with his gallbladder

operation as stated. On a basic level, he was always the last in the queue to get treatment.

47. Dad experienced problems with the treatment he was given to clear HCV. He was on the waiting list for a third attempt with Harvoni and he did get it eventually in 2017. The third treatment was successful and it should have been made available to Dad much sooner. The delay was put down to money and funds. It was a better treatment with less side effects.

48. Dad also had trouble with his HIV treatment. He used to pick it up from the pharmacy at the hospital when he had his HIV check-up. They then started posting it to him but the amount of times the post was missed or not dispatched in time was horrendous. It caused a lot of problems.

49. My father did not receive any form of counselling or psychological support. I believe it would have helped and I still think it should be offered to my mother. I believe it would have helped all of the family. It affected us massively. .

Section 7. Financial Assistance

50. My father received a cheque through the post for £70,000 from the UK litigation in 1991. He used it to buy the house and took us on a couple of holidays after telling us he had won the football pools. He was forced to sign a waiverr. If he didn't sign it he was told nobody would get any money.

51. My father received funds from the MFT when it was first set up and later through the Skipton Fund. It was only when I started campaigning for Tainted Blood that my Dad started to open up to me about everything. I then helped him with his finances and made sure he was getting what he was entitled to. He was getting a monthly payment from MFT and Skipton until the EIBSS took over.

52. There were big hoops Dad had to jump through to get some of the payments to include people coming over to our house to 'assess' him. I think it

disgusting for Dad to have to justify himself when he was infected with these deadly viruses and just expected to go away and die within 3 years. When I contacted the Scheme after Dad passed, I was told the payments would stop. All that was then available to my Mum was a one off £10,000 and a funeral allowance of £3,500. It wasn't until a year later that I started doing some digging with another campaigner. I found out that Mum had missed out on money she was entitled to for over a year because we were misinformed.

Section 8. Other Issues

53. My wife and I had our own children and when I told the health visitor about my father she seemed put off and never came back. Life seemed to carry on. Dad was going to work and it all seemed to fade into the background until I found Tainted Blood. I asked Dad if he minded if I started campaigning. He told me to do what I wanted as long as it was all no names and no addresses. I found out things I didn't really want to. To see your dad so slowly deteriorating is very hard. I didn't dare say anything to anyone. Any other illness you could tell people about and talk about it but I couldn't. I had no one to talk to. It still weighs on me and doesn't go away. My Dad should still be here. My Mum and I were the main carers of my Dad and at the time I was also my wife's carer.

54. The infections ripped my family apart. Trevor, my brother, found a letter in Mum's handbag when he was young saying about Mum being tested for infections and he confronted Mum and Dad about it. There was a huge family argument and Mum tried to convince him that it was not what he thought. It destroyed their relationship. It had a huge effect on our whole family. We never even spoke about it between us. I might mention to Dad about the campaigning and what I had been doing but that was the extent of it. We respected Dad's wishes and he didn't want to talk about it.

55. I was involved in campaigning for many years because of the injustice. It ripped our family apart. I work with Tainted Blood and the things we found out

are horrendous. Sometimes I wish I never delved so deep because of the things I found out.

Anonymity

19. I do not wish to remain anonymous.

20. I would very much like t to give oral evidence to the Inquiry if the opportunity should arise.

Statement of Truth

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

Signed **GRO-C**

Dated 21 - September 2020