

Witness Name: Collette Helen Mackey

Statement No: WITN5232001

Exhibits: WITN5232002

Dated: NOVEMBER 2020

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF COLLETTE HELEN MACKEY

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I, Collette Helen Mackey, will say as follows:-

#### **Section 1. Introduction**

1. My name is Collette Helen Mackey. I was born on **GRO-C** 1978 and I live at **GRO-C**.
2. My husband, Paul Christopher Mackey (born on **GRO-C** 1969), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII). He died as a result of Carcinoma of the Oropharynx on **GRO-C** 2020, aged 51.
3. Paul provided his own Statement to the Inquiry on 2<sup>nd</sup> April 2019 (WITN1360001) and it should be read in conjunction with this Statement. This

witness statement has been prepared without the benefit of access to Paul's full medical records.

## **Section 2. How Affected**

4. Paul had mild Haemophilia A and was treated with FVIII concentrate on just two occasions at the Southport General Infirmary during 1977 and 1983. He was told that he was HIV positive in 1994 by Dr Woodcock.
5. I refer specifically to paragraph 30 of Paul's Statement in relation to him being infected with HCV as a child. Paul was informed that the infection had cleared itself and was no longer active.

## **Section 3. Other Infections**

6. Paul was also advised that he had been put at risk of vCJD.

## **Section 4. Consent**

7. I refer to Paul's Statement.

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

8. I refer to Paul's Statement but feel that I have to describe the suffering Paul has had inflicted on him over the time we have been together because someone should be shouting about what happened to him, me and us, and because it doesn't seem fair that it had to be him!
9. I met Paul in 1999 and, although it was clearly difficult for him, he told me straight away about being infected. I was 20 years old but had never heard of the contaminated blood scandal which in itself is an indictment of the situation. I was totally shocked to hear such a thing could have happened. It changed

how I felt about the NHS. I went from having complete faith in them to being fearful of what they were capable of and, obviously, distrustful of them, something which has only grown and been compounded over the years of further mistakes, neglect and downright dangerous behaviour on the part of the medical profession.

10. We had nearly a year together from meeting before Paul fell gravely ill with volar tuberculosis (TB), which would have been impossible to contract if not for the HIV infection. He was only the third person ever to be infected with this disease. We lived out in the countryside in Wales and he was prepared to suffer every day for months and months with the extreme effects of that illness to include coughing up blood, daily fevers, exhaustion, extreme appetite and weight loss as well as waking many times every night with sweats and fevers, taking dose after dose of paracetamol and waiting for each fever to break. It was agonizing, real suffering, and yet he would rather that than face the nightmare that was going to the hospital, a place that for many is somewhere to go for comfort and healing. To Paul, it was only a place of cold lack of care for him. I had no idea how to deal with that at the time. I had no idea who to call, no idea of who to ask for help and no idea how to get him help.
11. During Paul's stay at the Liverpool Royal Infirmary over the months it took for him to recover enough to come home (although they saved his life and I'm obviously grateful for that), there was a general lack of day to day care and I provided all his meals.
12. At this point they started Paul on anti-retroviral medication. His immune system was so damaged at the time (his CD4 count was zero and his viral load was hundreds of thousands) that he had a severe reaction to the drugs starting to work. He had fevers of 40 degrees, sickness, numb feet, really weird dreams and various other symptoms. Fortunately, the drugs worked well and he continued on the same combination. I was always involved in Paul's medical care and I would sort his pills and give them to him every day.

13. After Paul's recovery from TB, his reaction to the anti-retrovirals and our return to Wales, his haemophilia appointments were kept at Liverpool. This meant that each appointment to include travelling etc lasted a day instead of the hour or so the appointments were at Glan Clwyd GRO-C  
GRO-C. The build-up/dread of each appointment lasted for days beforehand and we were forced to worry about Paul's treatment. I was constantly worried as to how he would get treatment if a serious bleed occurred and we had to travel all the way to Liverpool for FVIII concentrate. It could have easily meant the difference between life and death for him and it also meant that when Paul did have a bleed (for instance one into his hip and the ambulance took us to Glan Clwyd instead of straight to Liverpool), they didn't know about him at Glan Clwyd and they wouldn't there believe he was a haemophiliac. This left Paul without treatment for many hours resulting in more suffering. He once had a bleed into his gut and they came to collect him in a non-emergency ambulance (little more than a taxi really) and within an hour of being taken to Liverpool, Paul was on the phone to me. He was walking down the side of the road trying to get a drink as they wouldn't give him any water. He had next to no blood in his body and they allowed him to leave the ambulance at the side of a main road after giving him no care whatsoever. I can't tell you how scary it is to get a call like that and learn that the people who you have handed your seriously ill husband over to for help, people responsible for saving his life were so callous and downright careless that they would let that happen is unforgivable. After arriving at the hospital, he was then abandoned in the A&E for hours to suffer again.
14. Paul had a night-time seizure at home a few years ago and was taken to Liverpool hospital with severe back pain then discharged to journey home alone on the train, without anyone trying to arrange travel or any pain relief. They then arranged an MRI. When Paul told them his back was agony and that there was no way he could stay still during the MRI as required, they didn't arrange any pain relief and a whole journey to and from Liverpool for the appointment

was wasted. When they finally x-rayed Paul they found he had cracked a vertebra. They had sent him home on the train with a broken back!!!

15. At this point, they insisted on an MRI for which they provided pain relief and Paul managed to endure it. We told them that Paul had had a previous MRI in hospital when recovering from TB in 2001 and evidence of old bleeds to the brain were then identified (not surprising for a haemophiliac). They chose to ignore this and insisted on us making a further journey to Liverpool to impart the results and the results were exactly the same as the last time. We insisted that they looked again at the previous results which confirmed this. Paul had endured more needless stress. It was just one incident of negligence after the other, stacking up and leading me to feel we were unsupported and left to pray that Paul wouldn't be left relying on further help. I genuinely feared that one day they would succeed in finishing the job and Paul would be dead through their neglect.

16. Paul's treatment and care then moved back to Glan Cwyd. The move was not easy. Paul had to arrange everything himself and when complete he received a letter from the sexual health clinic at the hospital saying his appointments would take place under that department. It was highly inappropriate in Paul's case and mistakes continued to be made to include the need to repeat blood tests due to laboratory error the last lot of blood tests.

17. Many times over the years Paul had bleeds into his joints resulting in extreme swelling, pain and bruising. He stayed at home with bed rest as a treatment rather than requesting medical intervention.

18. Paul and I tried every day to live our lives in a peaceful, happy and positive way relying on our strong beliefs to make sense of everything, practicing Krishna consciousness. Paul learned to make and play violins as well as many creative artworks to help him and I enjoy nature photography. I cannot stress how much the behaviour of the Government affected us in covering up and ignoring what they have done. Their mishandling of such a terrible crime, possibly worse than

the initial crime itself, affected Paul's view of a world in which he didn't trust people generally and always expects the worst from them. I can only see that that was as a direct result of his infection and his treatment post infection.

19. The inability of the entirety of Paul's family to communicate with him about what happened to him, caused difficulties in their relationships. Paul remembers turning yellow and being very ill through hepatitis as a child. The fact that he was co-infected with HCV and HIV during his childhood and only informed that he had HCV in 1994, appeared to carry little weight with them.
20. When Paul and I met, his daughter Jade was 8 and Paul was in the middle of a very difficult custody struggle with Jade's mother Lyn. He never gave up on pursuing a relationship with Jade and up until she was aged 15, we jumped through every hoop thrown at us. It was worth it and Paul and Jade became very close and always had a fantastic relationship.

#### Recent events (post April 2019 when Paul submitted his own Statement

21. In October 2019, Paul having suffered with a bleed in his jaw for a long time (a very worrying and painful thing he endured alone purely out of fear of further bad hospital treatment) noticed that the problem had progressed to a bleeding ulcer inside his mouth. Given that he had started bleeding out, we knew that it was no longer an option not to go to hospital. At 4am on a Saturday morning, I rang all the right people to include the Haematology Department (they are difficult to get hold of, particularly as at weekends they operate on skeleton staff basis at best) to say that Paul was on his way to A&E and also to beg the admissions desk to treat him well and look after him. In that situation and as ever, I told them exactly what Paul needs, treatment with FVIII concentrate and (as ever) you are told in response that everyone is ready for him and that it is going to be fine. After finally convincing Paul to go to the hospital, one can only imagine my horror when he arrived back home within an hour with no treatment

given, still bleeding out and getting weaker. I phoned again to be yet again reassured that all would be well and I then had to convince Paul to go there again, only for him to return a second time without treatment. To add insult to injury, Paul was sent away after abruptly being told that 'you can't turn up at hospital and demand treatment'. So we both suffered yet another unnecessary day with Paul losing blood until finally at 4am Sunday morning I could stand it no more and we both attended at A&E to a frankly hostile reception. Paul was left waiting with severe bleeding whilst they tried to find out what sort of treatment to give him (and if they are going to give any at all). Finally, at around 11am, Paul was given a very small dose of FVIII with only follow up advice to come back on Monday at 9am when more staff would be available. FVIII concentrate only works in your system for 12 hours, leaving Paul to start bleeding again at 11pm the same night. Trying to tell everyone this to no avail and still being offered no further treatment, resulted in Paul being left to bleed for hours.

22. Despite assurances that everyone would be ready, at 9am on Monday, being the first on the ward, we were met by blank faces. We turned up to confusion. All the nurses want to help (they are the only comfort available and in the main they do their best) but they have no power over the actual treatment. In that situation, you ultimately tell different sets of people, nurses, doctors, the lab etc etc the same story over and over. One doctor tells you 'No problem, treatments will be every day twice a day'. You turn up and another doctor says something different again with Paul still bleeding, still in pain and to even get a small amount of treatment agreed doesn't necessarily mean that the staff know how to administer it and they cheerfully tell you this before giving it, causing many terrible bruises. Paul was still bleeding (left unfixed) and in pain as they then booked him in for a CT Scan. To top it all off, we were later told by the doctor familiar with Paul (in charge of his care before moving) that she couldn't understand why he was treated with so little FVIII concentrate. We were told that our only option if it got worse 'out of office hours' was to go back through the nightmare of admission through A&E.

23. After having experienced this nightmare and much more bad treatment over very many of the following weeks (involving sporadic treatment on alternative days and no treatment at all over weekends leaving the bleed to worsen) and after us begging them on a daily basis for normal consistent treatment with factor allowing Paul to get his levels up, we finally got enough factor treatment to then come to the realisation that it wasn't a normal bleed after all.
24. The Royal Liverpool haematology team got involved and Paul was given sufficient treatment to finally get his rotten teeth removed (something he had been asking for, for around 8 years). We were told that Paul needed a biopsy. The biopsy revealed a squamous cell cancer needing intense radiotherapy and chemotherapy treatment. In the time between first visiting the hospital and the start of the radiotherapy and chemotherapy, the lump had grown enormously to around the size of a cantaloupe melon just on the outside of his mouth. The treatment caused Paul even more awful suffering and, whilst the lump had completely gone on the outside, it never felt any better to Paul on the inside. He was in immense pain. He was unable to eat and lost a lot of weight.
25. Paul suffered immensely with constant pain and despite the results coming back as encouraging Paul never felt any better. On GRO-C this year at approx 4am Paul woke me. I turned on the bedroom light and saw there was blood everywhere and that he was bleeding profusely from his mouth. He died within a couple of minutes. I was told the cancer had eaten away the arteries in his neck which caused a catastrophic bleed. The way he actually died was extremely traumatic for me and, although I'm glad he wasn't in hospital alone (as he would have hated that) and that we were together at home at the end, I have nightmares and flashbacks to those moments. I'm not sure if or how I'm ever going to get over this or ever feel 100% ever again.
26. Paul's treatment was delayed firstly by his immense, justified distrust and outright fear of the medical professionals in charge of his care (which stems directly from the infection with blood products in the first place) and his



treatment by them since (detailed in this Statement above). The unwillingness by Dr Manan at Glan Clwyd Hospital to provide sufficient FVIII treatment to deal with the bleed delayed the cancer diagnosis. The cancer treatment given appeared to be working. I can't help but think that had Paul got the treatment quicker he might still be alive.

27. I refer to Exhibit WITN5232002 being a letter from Dr Win Soe, Consultant Oncologist dated 13<sup>th</sup> October 2020. The letter confirms that patients with HIV are unable to fight cancers such as oropharyngeal cancer well and can actually cause HPV related cancers. I feel cheated, a widow at 42 losing my husband who only made it to 51 years old, another victim of this scandal, another death and more blood on their hands.

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

28. I refer to my previous comments above.

#### **Section 7. Financial Assistance**

29. I refer to Paul's Statement.

30. The MacFarlane Trust left us floundering for years with what they now admit was not enough to live on. They gave us poor financial advice. Instead of paying off the debts we had (which we later discovered should have been done by them as a matter of course for us and am currently left with a second form of mortgage), they ignored us for the most part. If they had been more helpful, our quality of life before Paul died could have been improved.

31. We received the motability payment via the Disability Living Allowance for the whole time we were together until one of his last PIP interviews (a few years ago) when they scored him zero points and removed the payment leaving us over £300 a month worse off.

**Anonymity**

32. I do not wish to remain anonymous and 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.....

09/12/2020