Witness Name: Keith Trowell
Statement No.: WITN6262001
Exhibits: Nil
Dated: 10 September 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KEITH TROWELL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 August 2021.

I, Keith Trowell, will say as follows: -

Section 1. Introduction

1. My name is Keith Trowell. My date of birth is GRO-C and my address is known to the Inquiry.

2. I have just turned 70 years old and I retired from work in November 2020. I have worked in local government all of my life from 1970 until last year in which I've always been in the legal department. I live at home with my wife and I have six children in total. Two are from my first marriage and four are from my second marriage. All of my children are grown up ranging in age from 26 years old to 50 years old.

3. I am a mild haemophiliac. There is a history of it in my family: my uncle was a severe haemophiliac – so much so that he was a wheelchair user because of the damage to his joints. I intend to speak about my infection with hepatitis C ("HCV") that I got as a result of treatment with blood products and my diagnosis with hepatocellular carcinoma cancer ("HCC"). In particular, I will speak about the nature of my illness, how the illness affects me, the treatment I received and the impact it had on my life and my family.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. As a small child (pre-school age), I was tested for haemophilia at Bromley Cottage Hospital and at time, they said I didn't have it. It was just accepted that I bruised easily and there was no further monitoring. GRO-C GRO-C As the quality of the tests had advanced since I had taken them, and I had had some bleeding episodes in the intervening years (for example, a particularly bad rugby injury in my early teens), I was also re-tested. At that point, when I was around 15-16 years old, I was diagnosed with mild haemophilia.

6. Up until mid-1960s, I had no treatment for my bleeding disorder. Sometime during the late 1960s or early 1970s, I had my first treatment. It was infrequent: there were often periods of years in between treatments. If I had surgery or a tooth extraction, I would have treatment with blood products prior to it. If I had a major trauma (like when I accidentally hit myself with a wooden mallet), then I would have treatment. But those occasions were few and far between. I recall that I was treated with cryoprecipitate at some point, but I do not remember further details. I was treated with Factor VIII too. I think there was a move away from cryoprecipitate to Factor VIII at some point. All my treatment was at University Hospital Lewisham ("Lewisham Hospital"). Initially, I

was treated by Dr Whitmore. For the last few years, I've been treated by Dr Kumar (although that is not his full surname).

7. I wasn't really aware of any problems concerning contaminated blood until much later on. I suspect, but don't know, that I could have had a contaminated blood product sometime in the mid-1970s. I think this because around 1979/1980, I experienced jaundice. I recall when I had the jaundice, I could hardly get out of the chair and get across the room. I was definitely infected with HCV before I was married in 1982. No connection was made by myself or anyone else between that and my treatment with blood products at the time. My parents were never warned of the risks of being exposed to infected blood products.

8. A few years later, around the mid-to-late-1980s, I was told that I had non-A, non-B hepatitis. I do not remember when I was told but I can surmise that I was told at one of my regular consultations at Lewisham Haemophilia Centre. Subsequently, that was then relabelled as hepatitis C. At that time, it didn't seem to be regarded as a big deal. There was a lot of publicity about people being infected with HIV and HCV, but the doctors did not seem to make a big deal of HCV. I thought that I was one of the lucky ones to not have HIV. So, I was not unduly perturbed, but it was a general concern.

9. I was monitored from then onwards, fairly regularly, in terms of my liver function. I was told everything was fine – there were no ill-effects from the HCV infection. They said, however, there might be a problem in 10, 20- or 30-years' time. It did not seem like a big deal at the time.

Section 3. Other Infections

10. I do not believe I was infected with any other infections other than HCV as a result of my treatment with blood products.

11. I received a warning letter about vCJD and a potential exposure to it through someone who donated blood products that I later received.

Section 4. Consent

12. I do not believe I was ever treated or tested for anything without my knowledge or consent. Where my data has been used for research purposes, it has been with my full consent.

13. I always consented to routine blood tests as part of my haemophilia treatment, but I do not recall being told I was specifically being tested for HCV.

Section 5. Impact

14. Having hepatitis C has had a worrying effect both on my wife, Angela, and me. It's been in the background for a long time. Being diagnosed with HCC has been devastating and hard to cope with. I think my wife is affected more than I am and, to a certain extent, is in denial as to the seriousness of it. We're still in recovery from the loss of our daughter, Natalie. Both of these things put together, I think she has difficulty coming to terms with it all. We find difficult to talk about these subjects and probably do not talk about it as much as we ought to. I think Angela has a very difficult time. For both of us, we have an 'act' that things are much better than they are. We did not tell my mother before she died that I had HCC. Angela also didn't tell her father, partly to save him worry.

15. Angela is quite resentful of the fact that I have been infected with hepatitis C. She feels that the medical professionals had not been as open as they ought to have been. She is of the opinion that there should have been a greater warning and alertness in the way they handled things. She finds it difficult to understand how I could be told out of the blue that I have HCC when I was consistently told everything was ok.

16. I suppose for years there has been a cloud over me because of the HCV infection. But that cloud has become considerably darker in the last few years because of the HCC.

17. We haven't told our children any more than the fact that I have a tumour. We haven't told them about the prognosis. They are largely unaware of it other than knowledge of what my treatment entails. The one exception is my daughter, living in Canada, who is a health professional. She researched my condition and got scared by it.

18. My infection with HCV and subsequent diagnosis of HCC obviously has had a major effect on coping with life generally. I have kind of taken the attitude from early on that I will carry on as normally as I can for as long as I can. I have been seeing a healer since 2018 for regular sessions – that has helped me cope psychologically with the liver cancer diagnosis. Without that support, I would have found it even more difficult to accept the position that I am in. In addition to the medication prescribed, I take some Japanese herbal remedies. I think the combination of doing these things helps me cope with the situation.

19. I worry a lot about how my family will deal with my not being there, both in terms of my physical and emotional presence but also in terms of the financial impact. That is a very considerable and heavy worry to me. I do not have life insurance. I did previously have a policy but got rid of it due to some financial difficulties. When my financial situation improved, I did not consider getting life insurance because of the obvious difficulties with my health condition. I have a substantial pension from nearly 50 years at work which would stop when I die. The financial support that I get from the Infected Blood Scheme will also come to an end (albeit that there may be something for surviving spouses). It is a constant, ever-present worry.

20. I retired November last year. After retirement, the plan had always been to go travelling. However, now I am reluctant to spend money on foreign travel because I worry about Angela not having sufficient to live off when I'm not around. It's also a worry in terms of planning future things. When I went to Scotland this year, I had booked it a year in advance not knowing whether I would still be alive by the time of the trip. That's the thing now: you think about 'next summer' or 'next year' but the reality is, I may not be here. I've been made very aware of the fact that although the current treatment is working extremely well now, there will come a point that it is very likely to cease to be effective. At that point, there may or may not be other options available for future treatments.

21. I don't think hepatitis C has affected my social life. I made some people aware that I was HCV positive. I haven't suffered any adverse reaction or stigma from it. However, I'm certainly less sociable since the HCC diagnosis.

22. In the main, until more recently, having hepatitis C had little effect on me. It wasn't until the end of the mid-1990s/early 2000s that it became a concern. When I was initially told that I had HCV, I was not really aware of the potential long-term consequences. Therefore, I was not unduly concerned that I had been infected. I obviously knew that I hadn't got HIV but I think that I was told that although I hadn't got HIV at the time, it couldn't be guaranteed that I hadn't got it until some years had passed.

23. From the failed interferon treatment in the mid-1990s, and particularly at the beginning of the 2000s, there was more talk about trying to do something about the hepatitis C because of the potential for a deterioration in my liver later on. That is when the alarm bells started ringing in my own mind: I realised hepatitis C could be more serious than I initially thought it to be. The doctors alluded to the fact that at some point I could have a serious deterioration in my health.

24. The results from my liver tests and conversations with doctors gave me a false sense of security. I accepted what the doctors said on the basis that I was being tested regularly. It reassured me. There were conversations about whether I should have a liver biopsy. I was not particularly keen to go ahead with the procedure due to my haemophilia. I had discussions with doctors at the time where I expressed that I felt it was premature to have a biopsy given that the test results were within the acceptable parameters. No efforts were made to persuade me to have a liver biopsy.

25. I have had two Fibroscans at St Thomas' Hospital. The first one was in 2011 and the result was 4.6 kilopascals ("kPa"). In July 2015, there is a letter that shows a liver stiffness measurement of 4.8 kPa (i.e. below the range of values typically associated with fibrosis). I have a letter from August 2017 that states that I am non-cirrhotic.

26. I didn't suffer any significant side-effects from my hepatitis C infection, although I have been careful to not leave blood-stained tissues laying around if I accidentally cut myself. Work colleagues were aware that I had hepatitis C, although no additional precautions were taken as a result.

Section 6. Treatment/Care/Support

27. In the first half of the 1990s, having hepatitis C became more of a concern. The doctors at the clinic started talking about possible long-term effects. They talked about the possibility of developing cirrhosis at a later point, although there were not any immediate concerns.

28. In 1996, both GRO-C and I were put on a course of interferon at Lewisham Hospital. I self-administered the treatment two or three times a week via injection. We both had flu-like reactions to it. I felt quite lousy in the 24-48 hours after an injection. After about three months, it was not having any effect on

course of treatment because he had a different genotype. I am genotype 1a which is known to be less responsive to anti-viral therapy.

29. There were various conversations about other possible treatments. Doctors said we ought to be thinking about further treatments even though there was no immediate problem.

30. It was fairly quiet for a while then. In 2002 I received a letter, addressed to my GP, from Lewisham Hospital saying that, given that I contracted HCV through contaminated blood products, treatment ought to be pursued. There was a build-up for some time towards having treatment of one kind or another. There was talk of triple therapy treatment. That didn't happen - for various reasons – until 2013. It was delayed because I had some mental health issues to deal with. There was no single reason triggering those mental health difficulties. Although my HCV infection was a contributory factor, other more potent factors were present. That included losing our daughter in 2009 which is what took me over the edge. It was a very difficult time. I had some counselling and was on anti-depressants for a while. I was also due to have ankle surgery which again didn't take place until March 2013. They decided it was best to delay the triple therapy until after that surgery.

31. The triple drug therapy started in September 2013. This was a combination of pegylated interferon, ribavirin and telaprevir. From the outset, I had adverse reactions to that therapy including rashes and a lack of energy and within 4 weeks of starting the treatment I had become severely anaemic. In November, I was prescribed folic acid and I later had some blood transfusions to raise my iron levels to combat the anaemia. It culminated on 18th December 2013 when I was admitted to Tunbridge Wells Hospital with complete renal failure and heart complications, in which I came pretty close to death. I was transferred to Guy's Hospital overnight where I was put on dialysis for a short period of time. I responded well to that and recovered from it. I was in hospital for about a week and was discharged on Christmas Eve to go home for

Christmas and I was readmitted to hospital on the 27th December for review and no further dialysis was needed. My kidney function had picked up at this point, but, of course, this illness meant that the treatment for my hepatitis C was immediately suspended. That was the end of that course of treatment.

32. Again, the monitoring of my liver function seemed to be within normal parameters and there were no big alarm bells were ringing anywhere. There was no immediate concern but obviously, there was still a background worry that because the HCV was still there, it could have consequences at some point. Things then drifted along for another couple of years or so. In July 2017 I was reviewed in the gastroenterology department at Lewisham Hospital and further treatment for the HCV was discussed. There were other treatments coming online that I could be considered for, so I had some preliminary assessments with a view to starting a third treatment.

33. During those pre-tests, they noticed high AFP levels (a marker for HCC). They conducted various investigations including a CT scan in August 2017. I remember being very surprised when I was then asked to go for another scan the following week. I thought they had made a mistake, but they had spotted something on the first scan so they wanted to re-do it. Following that second scan, they arranged an urgent meeting. As a result, on 21st August 2017, I was diagnosed with advanced HCC (liver cancer). Dr Suddle, a Consultant Hepatologist at King's said that the predominant aetiology was chronic HCV infection. I saw Dr Sarker on 18 December 2017 who informed me that the tumour spread to the portal vein and, as a result of that, it was inoperable and incurable. This diagnosis came as a complete shock given that up until then they were saying everything was basically ok.

34. The clinicians told me that the average life expectancy was about 18 months. Here we are some four years later, and I'm still here. I started treatment with Sorafenib in October 2017. That – touch wood – seems

to have had the desired effect in stopping any further development of the tumour. I'm still having the treatment for it. There are various signifiicant side-effects although it is difficult to differentiate what is a side-effect of the cancer and the medication for it.

35. I was reluctant to consider further hepatitis C treatment after my previous episode in 2013. However, after starting treatment for my liver cancer with Sorafenib, the clinic at Kings College Hospital told us that a further treatment to clear the HCV was available and recommended for their HCC patients. As a result, I began a course of Epclusa. I started taking that as a 12-week course on 14 February 2019. I had to wait for a further 12 weeks after its completion to see if the hepatitis C had disappeared. In August 2019, my HCV RNA PCR test results showed that my hepatitis infection was not detectable. The treatment had been effective and I was clear of hepatitis C.

36. With hindsight, I think I wasn't given enough information about HCV. But, at the time, I did not appreciate how serious it could be. I remember being told that the risk of sexually transmitting HCV to my wife was low. Other than that, I don't recall being given any advice on hepatitis C. Up until the mid-to-late 1990s, I wasn't aware that it was a particular concern for me.

37. I was not offered any counselling or psychological support as a result of my hepatitis C infection, although I was offered support from Macmillan Cancer Support after my HCC diagnosis. The hepatitis C infection seemed to be treated as a non-event. It was only after the beginning of the 2000s onwards that the doctors acknowledged that it was something to be dealt with as it could cause serious problems.

38. My dental care has been affected. I had to have some teeth extracted but there was a lot of 'to-ing and fro-ing'. Previously, I had a tooth extraction at Lewisham Hospital and I would have treatment with blood products prior to that. So, with later trips to the dentist, I knew I would

have to be referred to the hospital. I asked the dentist for that referral to Lewisham. Instead, they referred me to Queen Victoria (the hospital in East Grinstead) in January 2018. Queen Victoria Hospital said they wouldn't touch me because of my medical history with haemophilia. The dentist then contacted King's College Hospital to be treated there. I went to Lewisham Hospital for treatment with blood products prior to going to the dentist at King's and returned to Lewisham afterwards. The dentist at King's was fully suited when treating me.

Section 7. Financial Assistance

39. I received a Skipton Fund Stage 1 payment of £20,000. I do not remember exactly when or how I received that. I think GRO-C first mentioned the Skipton Fund to me. I also receive an annual payment of £3,500. When I was diagnosed with HCC, I successfully applied for Stage 2 payments. At that point, I received £50,000.

40. Although the process was simple and straightforward, I do not think the financial assistance is adequate. For those who lost their lives, and those lost in grief, the payments are not sufficient. But the payments have helped to prepare my family financially for when I'm not there. I'm one of the lucky ones; it could have been a lot worse.

Section 8. Other Issues

41. I have not obtained a record of what blood products I have received because I have not attempted to do so. The only time I have asked for my medical records are in relation to my Epclusa treatment for HCV.

42. This Inquiry should have happened sooner. Clearly, something has gone dreadfully wrong and needs to be looked at. There is plenty to suggest that people knew it had gone wrong and allowed the situation to continue. However, I question the value of it so late in the day when so many people have suffered and been affected with hardship. Part of me

asks what good this is some 40 or 50 years on from the events in question. It seems to me there is no real justice in it. I appreciate the fact that it is happening, but it should have been done sooner. I hope it will prevent anything like this occurring in the future. It is too late for many people. Hopefully there will be some kind of equity for those bereaved and survivors.

Statement of Truth

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

Signed GRO-C

Dated 10th September 2021