

Witness Name: Peter Baker

Statement No: WITN6413001

Exhibits: 0

Dated: August 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PETER BAKER

I, Peter Baker, will say as follows:-

Section 1. Introduction

1. My name is Peter Baker. I was born on GRO-C 1964 and I live at GRO-C
GRO-C Kent GRO-C.
2. I was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my medical records.

Section 2. How Infected

4. I have severe Haemophilia A.
5. I was under the care of the Haemophilia Centre at Lewisham Hospital initially and I was treated with plasma and cryoprecipitate. I then transferred to Lord Mayor Treloar College Haemophilia Centre, Holybourne, Alton, Hampshire, Alton, Hampshire in the mid-1970s when I started attending school there at 10 or 11 years of age. I boarded there until I was 16 alongside a large cohort of fellow haemophilia patients. I was under the care of Dr Reynolds and then Dr Wassef and Dr Anthony Aromstan. Whilst at Treloar College, I was regularly given Factor VIII (FVIII) concentrate.
6. No advice or warning about the risk of infection from FVIII treatment was given to me or my parents beforehand. I remember that my mother was very excited about FVIII concentrate. She had lost her brother at the age of 24 through lack of effective haemophilia treatment. FVIII concentrate was thought to be a wonderful thing for haemophiliacs. It was hailed as ground-breaking treatment. Before we came across FVIII concentrate, my mother had to call an ambulance to get me to the hospital for treatment as she didn't drive, and the hospital was 20 miles away, a good forty-five minutes drive from our home. With FVIII concentrate, she was taught to treat me herself and she could give it to me at home at weekends and during holiday time. She was thrilled.
7. I went to college after leaving Treloars and my treatment was covered by the Pembury Hospital for a couple of years. I was then covered by Maidstone Hospital where I was doing my nursing training and it was there that I found out that I was infected with HIV in, what I recall was around, 1984 or 1985.
8. I had not been aware of any concerns or issues whilst I was at Treloars College and I believe that I became infected whilst there. In 1984/1985 news of the

HIV/AIDS virus had begun to emerge. I had career aspirations and was training to be a psychiatric nurse at Maidstone Hospital. Dr Williams (Consultant Haematologist) spoke to me at one of our regular 'get togethers' and said there was a possibility that some of the FVIII products were contaminated with HIV. He mentioned to me that they had developed a test to detect HIV and asked if I would be willing to provide a blood sample for them to send off to validate the accuracy of the new test (as part of the trial), and I agreed.

9. It took weeks for tests to come back at that stage. I had routine appointments with Dr Williams and thought nothing of it when he called me to come in. I was a cocky youngster and did not think for a second that anything could possibly be wrong with me. Dr Williams sat me down and said something like 'I am very sorry, but your test has come back, and it is actually positive'. I said 'OK, what does that mean?' and he said 'based on what we know at the moment, you are going to have quite a short life expectancy'. He said I could expect six months to a year and I honestly do not remember what else he said. I was blanking it all out at that point. I could barely understand let alone process what he was saying to me through shock.
10. I remember going on a bender after that meeting. I was completely smashed for days. I was 20 or 21 years old. If it hadn't been for one particular ward sister whom I worked under, I honestly think that that would have been the end of me. I turned up one morning still drunk and I think that she was ready to give me the biggest 'bollocking' when I just broke down in front of her. I remember her sorting me out and supporting me, but a lot of that period of time is very much a blur to me now. It was a very painful, overwhelming time.
11. I had to try to get my head around it to be able to tell my mother, stepfather and sister. My mother was devastated. She carried enough guilt as it was, because I was born with haemophilia. After some time and when I saw Dr Williams again, he advised me that unprotected sex was a 'no, no' and that I would never

have the option of having my own children. The months and then the years that followed weren't any easier for me emotionally and psychologically.

12. It wasn't until very many years later (in the early to mid-1990s) that I was told that I was also infected with HCV. I was living in Five Oak Green then and I was under the care of Dr Mark Winter, then at Margate Hospital. I was told that I had HCV by Dr Winter at a routine appointment. I was at that time in poor physical health and my CD count was all over the place. I was underweight and I had several chest infections.

13. Dr Winter identified my HCV genotype as being likely to respond successfully to clearing treatment and I was subsequently placed on the trial of pegylated Interferon (in conjunction with Ribavirin and another drug) sometime in the late 1990s. My physical health was far worse than even I realised back then (to include HCV liver damage). Years later I went to Dr Winter's retirement party and he introduced me to his colleagues saying 'I have known Peter for a lot of years now. When he first came under my care, I really didn't think he would be standing here with me now.'

Section 3. Other Infections

14. I was not infected with anything other than HIV and HCV.

Section 4. Consent

15. I believe that I was treated and tested without my consent and/or that of my parents and without being given adequate information. I believe that I was used as a guinea pig for research purposes. My mother always used to tell me everything related to my haemophilia and share information she was given, and

she never mentioned any form of trial. She was sent my school reports and that was it. What happened to the other boys in my cohort from school would have happened to me. I have no reason to believe otherwise.

16. I feel betrayed by the doctors at Treloars College. They were supposed to be there to care for us. They took the Hippocratic Oath to do no harm. The moment they knew there was any possibility of causing harm to us they should have put us straight back on cryoprecipitate. I really do feel betrayed.

17. Most of my friends from Teloars are now gone. I believe there are only 17 or 18 of us still alive and very few of us from the same year to me. Every time I heard of the death of another school friend was a set-back for my mental wellbeing.

Section 5. Impact of the Infection

18. As stated, the fall-out of being told that I had been infected with HIV in the mid-1980s was profound. I do not know how I got through my nursing training, but I did. I had to have several meetings/discussions with the School of Nursing and Occupational Health at the hospital to see if I could even be allowed to continue on with the course. As a psychiatric nurse you sometimes have to deal with aggressive people. As HIV is carried in the blood stream, questions arose as to the implications if I was for example attacked and started bleeding. There were so many complications and it was all so negative to hear and to think about.

19. I was allowed to continue my training and, somehow, I obtained my qualification. I then applied for a number of jobs at Maidstone Hospital without success. I was turned down for them all. I cannot prove that being infected

with HIV had something to do with it, but it is not an unreasonable inference to make as the HIV infection would have been on my record.

20. I had no alternative but to find agency and 'bank' work as an auxiliary nurse (now referred to as a health care assistant) mainly at Pembury Hospital and the Kent and Sussex Hospital. The work (and the pay) was not to the standard of my qualification.

21. I struggled to continue to work as I had a number of infections and my CD count was terrible until Dr Winter put me on the AZT trial. I gave up on pursuing a career in nursing altogether in 1993 when I had knee replacement surgery.

22. I didn't know what I could do for work after I left nursing. My partner (at that time) and I both wanted to run our own pub, so we embarked on a pub management course with a brewery and we loved it. We were coming towards the end of it when someone informed the brewery of my HIV status. At that, the brewery tried to get rid of me, insisting on an occupational health assessment although the doctor they sent to assess me told me that he didn't care what he had been told about me by the brewery because, as far as he was concerned, I was fit enough to do the job. Despite that, I was told by the brewery that they were unable to offer me a pub of my own at the end of the course and I would never be anything within the organisation than a relief manager, covering for other managers when they were on holiday and the like and doing a week here and a week there. My partner and I were devastated and after speaking at length about it, we decided to leave. I do not think the brewery would have got away with that if the same thing happened now.

23. I had had a good relationship with the manager of a company used by the brewery for cleaning. He approached me after we had left and he said 'I'm, really sorry about everything that happened to you'. He went on to tell me that after my partner and I had left our pub accommodation he was told to deep

clean the accommodation to include burning our bedding. After that, I didn't tell a living soul that I was infected with HIV.

24. The stigma surrounding HIV/AIDS was horrendous. It affected everything and ruined all my relationships. Friendships were lost. My best friend I grew up with would cross the road to avoid me after I told him about my HIV status.

25. I struggled financially for years and years. I lost the home I originally bought when I was nursing as I couldn't pay the mortgage. I was severely in debt for a long time. I took out loans to pay off credit cards, the credit card debt would build up again and I had to take more loans. It is hard enough to have to deal with haemophilia bleeds and hold down a job without all the added health complications and side effects of the HIV and HCV treatment. Some people/employers do not even know what haemophilia is, but others do, and it is stigmatised.

26. After I had my HCV clearing treatment, I didn't know what I could do for work. I did a residential book-keeping course and was with one particular company for almost a year before that company was bought out and I lost my job. After that, I retrained as an accountant (with the Association of Accounting Technicians) and was offered a permanent role with AXA PPP Healthcare in December 2006. I have been there ever since and became a homeowner (again after many, many years) around six years ago. Up until then I rented. I found a mortgage lender prepared to include my EIBSS money with my salary when looking at my income. Life insurance has always been an issue. It just isn't available.

27. The welcomed stability of being in a permanent role for the last 15 years has finally brought me a little bit of peace of mind. The occupational health people at work knew about my HIV status but no-one I worked with did until a few weeks ago. I was at the Infected Blood Inquiry, supporting a good schoolfriend from Treloars who was giving oral evidence and after standing with the guys

from Treloars for a photo, I surprised myself by speaking on camera to a reporter from Channel 4 TV. Because of that and through social media, my work colleagues and other friends and acquaintances became aware of my HIV status and what happened to me. Whilst everyone has been brilliant about it, I have been struggling since. It has made me realise that, whilst I thought I was coping, I wasn't actually coping well at all. I cannot help but think about all that we have been through and the boys we have lost. Every time I hear of another death (and when I heard about the memorial to the boys at the Church at Holybourne) it triggers a downward spiral in my mental health. Listening to the evidence at the Inquiry, has left me feeling like a hidden box has been opened and tipped upside down. I have been signed off from work with depression and have been lined up for trauma counselling.

28. Being co-infected with the viruses and all that went with it is an incredibly difficult thing to live with and I have to try very hard to not let it affect my partner and children. I have amazing step children but I am gutted that I do not have children of my own. I really am devastated by that. The life I have led is not what it should have been and my dreams and aspirations have been taken from me.

Section 6. Treatment/care/support

29. I had what was very good care and support from Dr Winter. I don't think that I would be here today otherwise. My CD count stabilised when I was put on the AZT trial (in the early to mid-1990s) and I had a successful course of Pegylated Interferon (in the late 1990s).

30. I had to self-inject the Pegylated Interferon into my stomach every week. I couldn't do it and ended up travelling to and from Canterbury Hospital to have it done for me there. I went with Dr Winter when he transferred from Margate

Hospital to Canterbury Hospital. It was a one hour journey each way for me every week. The treatment was not pleasant to say the least and six months into the treatment I wanted to stop it. I was lethargic and I had brain fog, and I wasn't able to work for the entirety of the treatment period. I relied on my then partner's earnings, my DLA and sickness benefit. The worst of it was the depression as I was so down. Dr Winter encouraged me to continue past six months, telling me that I had a good chance of clearing the virus if I could just stick it out for the full year.

31. The HCV infection levels have remained undetected since then, but I have ongoing liver function tests. I have to be careful with my diet and cannot drink too much.

32. I didn't give health professionals to include dentists the opportunity of treating me poorly. Dr Winter arranged for me to see the NHS hospital dentists if I needed dental work. I have been with my current dentist for the last 20 years. He knows I have HIV and he is great as is my hygienist (a young woman I have also seen for several years).

Section 7. Financial Assistance

33. In addition to the MacFarlane Trust payments, I have had the Stage 1 and the Stage 2 Skipton Fund payments (the latter payment for my compromised liver). I have recently received the parity payment through EIBSS. Because of the EIBSS income I am relatively comfortable now but back in the day it was a major struggle just to get by.

Anonymity

34. 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.....29TH NOVEMBER 2021.....