Witness Name: Michael Rose
Statement No.: WITN2701001
Dated: 15 June 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MICHAEL ROSE

Section 1. Introduction

1. My name is Michael Rose. My date of birth is GRO-C 1957 and my address is known to the Inquiry.

Section 2. How Infected

2. In early spring 1982, when I was 25 years old, I broke my right hip after a fall while visiting my parents. I was taken to Royal United Hospital in Bath, and had an operation to repair my hip which included inserting a pin and prosthesis into it.

3. About a year later, I went back to St Martin's Hospital to have the pin and prosthesis removed. I believe something went wrong during this surgery, as I remember waking up in a great deal of pain with a 9-inch open wound, and seeing that I was losing a lot of blood. At that point I believe I was given a blood transfusion to help me recover, although I do not have documentation of this.

4. I was feeling woozy at the time and don't remember exactly what was said about how I would be treated, but I do not believe I was told that I would be receiving a transfusion or that there were any risks involved.

5. Several years later, in 1986, I relocated to Los Angeles, California.

6. In about 1989 or 1990, I went to my general practitioner as I was not feeling well and thought I might have a chest infection. I ended up having a chest x-ray, after which I was diagnosed with pneumocystis pneumonia (PCP).

7. PCP was a known AIDS-related illness, so I was then tested for HIV. I was told why an HIV test was indicated and I consented to have it done. The blood test took three days to come back before I knew I was HIV positive.

8. The wait for my test results was excruciating. When I finally found out I was HIV positive, I was in shock. I had been very sick, to the extent that I couldn't walk, and I was extremely worried about what might happen to me. I was not given much information by my doctor at that appointment about next steps, but to be honest I am not sure I would have been able to take it in if I had, in the state I was in.

9. I confided in a friend of mine that I had just tested positive, and he took me to the AIDS Healthcare Foundation in Beverley Hills, who were very helpful. They were accustomed to dealing with people who were newly diagnosed with HIV and were able to discuss my options with me and tell me that I should find an appropriate doctor who specialised in HIV and AIDS .

10. I don't have any complaints about the way I was treated by my doctor or the AIDS Healthcare Foundation. I felt they were kind and informed and I was able to find out the information I needed.

11. At the time, no one asked me about my risk factors for HIV and I was not aware that I could have been infected by a blood transfusion. They simply told me what type of specialist to see for treatment. It was not until several years ago when I

read a Guardian article about the Infected Blood Inquiry that I realised I was likely infected by the transfusion I received.

12. I was not given any information about the risks of infecting other people.

Section 3. Other Infections

13. I was infected with HIV only.

Section 4. Consent

14. I did not consent to receive a transfusion, although I did sign a waiver before having the operation which may have contained something about this.

Section 5. Impact

15. The main impact that my HIV diagnosis had on my mental health was the anxiety I had whilst waiting for the test result. Once I found out my results, I was in shock and did not know what to think. It was devastating. I am very thankful for the friend of mine who helped me get the help I needed after I was diagnosed. I am also thankful to my husband, who I have been in relationship with since 1985 and who helped me cope with my HIV diagnosis and treatments over the years.

16. After speaking to someone at the AIDS Healthcare Foundation, I looked up specialists in the phone book and phoned the nearest doctor I could find. I then went to see him and he put me on a drug to treat my pneumonia.

17. Shortly after starting on this drug I developed shingles, which I had for about 2 to 3 months before the pain started to subside. For the first few weeks of having shingles I couldn't do anything. I had to constantly try to make sure there was nothing touching my skin. I'm a keyboard player and a lot of my work is teaching students piano, but I was not able to travel around and teach during this time. I

was worried about how long this would last, as I didn't feel I could tell the students what was wrong with me.

18. After a while my physical symptoms lessened, and I continued to take drugs to treat my HIV. My treatments have changed several times over the years as new medical advances have produced more effective treatment regimes. I cannot complain about any of my doctors or treatments I have received as they were the best available at the time.

19. Currently, my viral load is luckily very low. I believe it was about 30,000 to 40,000 at the time of my diagnosis and is undetectable now. My T cell count went from 5 at the time of my diagnosis to between 700 and 800.

20. I know that I am lucky in that my symptoms were quite mild compared to a lot of people who contracted HIV in the 1980s. However, I have had some lasting damage. One of the treatments I used to take caused serious damage to my kidneys. As a result of that treatment I developed a kidney stone and I am now in stage 3 kidney failure. I have also had significant dental problems which required me to have 4 root canals. I am not sure if the weakening of my teeth is a complication of HIV or the treatments.

21. I think that I would have been told about the potential side effects of the treatments I took, but in the end I would not have had much of a choice to not take them because managing my HIV was more important than any side effects I had.

22. I did not find that there was a significant stigma against people with HIV/AIDS in the communities that I lived in in Los Angeles, or now where I live in Palm Springs. There was lots of support available and I did not feel judged as a result of having HIV.

23. I did not face any difficulties in accessing treatment for my HIV. However, the cost of treatment could have been almost prohibitive at times. I work as a musician and am able to access healthcare at a subsidized rate if I can show

each year that my income has remained below a certain threshold. However, sometimes my income is slightly higher than the threshold and I have to rely on my savings to pay for healthcare costs. This year, my HIV related healthcare could cost about $25,000 in total, as a result of both drug costs (about $1200 a month) and the increased premium I pay as a result of having HIV. At the moment my insurance only covers $400 a month, so I have to make up the difference. I don't have that kind of money to spend each year, and it is incredibly stressful to try to figure out how to find it repeatedly, knowing that even if I put it on a credit card, I will have to find a way to pay it back and then will owe the same amount again in a year's time. Fortunately I have had my drugs covered by an AIDS organization set up by the government, and am now covered medically by the Affordable Care Act otherwise known as Obamacare.

24. I do not think that there were any treatments that were not made available to me.

25. I do not think that having HIV caused me any difficulties when accessing dental care or treatment for other conditions.

26. The impact of my diagnosis on my social life was devastating. However, I had a close group of friends and a good support network. The way I coped with it was just to not talk about it. The main worry I had at the time was that I would pass it on to my partner. I discussed that with him and we took precautions so that would not happen. I did not tell my family in the UK about it, but I eventually felt comfortable discussing it with my immediate friends here in California, and now most people know.

27. The most stressful part of having HIV for me is the continued cost of my healthcare. I currently work as an organist for a church, but we have not been working since last March due to Covid. They kept me on the payroll until August, but now I am only on half pay. The impact of having to save for medical care has had an impact on my longer term finances. In addition to always being worried about how to make the payments, I am concerned about having enough money

to get by in my later life. I am 65 and my husband is 77, so it is important to me to be able to save money to live by as we get older, but I have been unable to save as much as necessary because of my high healthcare costs. As I pointed out earlier, most of these concerns have been allayed.

Section 6. Treatment/Care/Support

28. I have not had any difficulties in obtaining treatment.

29. I was not offered any counselling at the time of my HIV diagnosis. Some years later, shortly after my mother died, I did see a psychiatrist and we discussed some of these issues.

Section 7. Financial Assistance

30. I have not received any financial assistance in relation to my infection with HIV. However my drugs are now covered by a federal programme.

Section 8. Other Issues

31. I hope that the Inquiry is able to achieve some accountability for what happened and some recognition that something went wrong.

Statement of Truth

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

Signed ...GRO-C

Dated ....15 June 2021.......................