

Witness Name: Gene David

Statement No.: WITN1862001

Exhibits: WITN1862002-WITN1862004

Dated: 14 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GENE DAVID

Section 1. Introduction

I, Gene David, will say as follows: -

1. My date of birth and address are known to the Inquiry.
2. I am 53 years old and have just moved from the UK to Spain to try and start my life over. I live with my partner of 18 years and our two dogs. I am currently working, on a self-employed basis, in interior design.

Section 2. How Infected

3. In June 1985 I visited the Charing Cross Hospital in Hammersmith, London, with a severe sore throat after a two week illness. On admission, I was referred to the ENT department and, on examination, I was diagnosed with acute tonsillitis of the left tonsil, which had developed into a Quinsy, an abscess of the tonsil. My mother was with me as she had come up to London

to look after me. I was prescribed antibiotics and advised I would need my tonsils removed, but only when the infection had cleared up. I went home to my mother's house in Devon whilst I recovered from the infection.

4. I attended my GP in Devon who noted in my medical notes that I was scheduled for a tonsillectomy in July 1985.
5. In July 1985 I again attended Charing Cross Hospital to have my tonsils removed. After the operation I spent three days on the ward and was discharged home to my flat in London.
6. During my first night at home I awoke in the night choking on blood. My mother called an ambulance and I was rushed back to Charing Cross Hospital, where it was discovered I had suffered a haemorrhage from the operation. I had lost a lot of blood and was given four units of blood by transfusion. It was difficult to control the bleeding and so I was also administered with a blood clotting agent, which I believe was Factor VIII. I continued to vomit congealed blood from my stomach.
7. After I received the blood products I was diagnosed with septicaemia after becoming ill very rapidly. I was not quite conscious much of the time. I was treated with IV antibiotics and fluids for a further month on the ENT ward where I was in isolation.
8. Following discharge, it took a long time to recover. I visited the GP in London on 8 January 1986 for a further sore throat. At the time I was working as a performer as I had a singing career.
9. In February 1989 I was in a relationship with GRO-C when he told me he had been diagnosed with HIV. I had never been to an STD clinic so I went to a private clinic in Harley Street, London, which was doing same day results. My

test result came back as antibody positive. I decided to go to the St Stevens Clinic in Fulham Road, London, now known as the Kobler Clinic. My diagnosis was confirmed two weeks later. At that time there was no treatment for HIV. I believe AZT was being trialled but my CD4 count was high, at 860, and I didn't qualify for the treatment.

10. I believe that I contracted HIV from the blood transfusion and Factor VIII given at the hospital. I had also been diagnosed as being Hepatitis B (HBV) immune, meaning I carried the antibodies to HBV although I had never been infected with the disease. I believe that I passed the virus on to GRO-C GRO-C and that my infection had only come to light through his diagnosis.
11. The treatment and care I received, and continue to receive, at the Kobler Clinic was excellent. I was initially seen on a monthly basis, dropping to every three months, and in recent years this has dropped to every six months.
12. I received no information or advice (about the risk of being exposed to infection through infected blood products before my operation at Charing Cross. At that point I had never really heard of HIV.
13. When I found out about the infection the doctors at the Kobler Centre gave me the relevant information about the infection. I was given adequate information to help me understand and manage the infection, including full and comprehensive information about the risk to others. I do not think they could have given this information to me much earlier because I had only just been diagnosed. The information regarding my diagnosis and results were handled very well and I was treated with dignity and respect by my health professionals.

Section 3. Other Infections

14. I believe that I was infected with HIV through contaminated blood from the blood transfusion and blood products, and I believe that I may have also been

given HBV antibodies in the same blood products as I have never had HBV infection.

Section 4. Consent

15. I do not believe that I have been treated or tested without my knowledge, consent, without being given adequate or full information, or for the purposes of research.

Section 5. Impact

16. Being HIV positive has devastated my life. It has turned me from a confident, outgoing, positive person into someone who is insular and scared: scared of contact with other people for fear of their reaction to me, scared of holding hands with my nieces and nephews when they were young for fear of passing anything on to them; scared of my family's reaction if they ever found out, scared of illness, scared of dying.
17. Since 1989 I have gone through life with one foot in the grave, never knowing if the next step will take me six foot under. At the age of 23 I was told I had HIV and that there was no treatment and no cure. When I asked how long I had I was terrified to learn it could be six to 18 months: none of the professionals at that time knew just how long anybody had.
18. I moved to London at the age of 18 to follow a career in music. Between 1984 and 1989 I had built a solid career. I was writing and performing my own songs and had appeared in many of London's night clubs and venues. I had toured Sweden, signed a record deal and my songs were signed to Warner Brothers publishing. I was working with renowned engineers and producers, and mixing with all the music industry stars of that period. I was booked for nights at the London Hippodrome and tickets to my performances sold well. I

had managed to buy two flats in Brixton and was living in one and renting out the other. Life was looking good, I had worked hard, and everything seemed possible.

19. The day of my diagnosis everything came crashing down. A big black full stop appeared before me and it came with the stigma of having HIV. I could tell no one, I could not get the answers to life that I sought, I feared touching people in case they found out, I lost all physical contact with the world around me, with my family, with my friends.
20. I felt dirty, the world around me felt I was dirty. I had to live in the shadow of fear and ignorance, and my heart ached for someone to guide me, to hold me and to say it would all be ok. But I could not approach anyone with this dirty secret.
21. I had no option but to try and live for the now, for today. I feared I would lose my record contract and no one would like me or my music because of who I had become. I embarked on a road of self-destruction, I drank and danced my life away waiting for the inevitable. I spent the money I received from my flats and they were repossessed. I gave up writing and performing, I lost my record contract, I became homeless and stayed with friends over the coming years.
22. The medications I have had to take have made me very ill over the years. At times I was unable to work or leave the house. I would sleep all the time, have night sweats and vomiting, diarrhoea, and suffer from depression. I have suffered several infections over the years ranging from Bell's palsy, pneumocystis pneumonia, C. difficile, high blood pressure, anxiety and skin cancer. The anti-viral medications have caused skeletal problems including osteoporosis.
23. It wasn't until 1996, when I was given social housing and receiving anti-viral therapy, that I could see the building blocks to some kind of existence. Still the

thought of never making it to the end of each year weighed heavily on my heart and mind. It was hard to maintain friendships, or to get close to my family. I lived in fear of holding my nephews and nieces as they came along, for fear of what my siblings would think if they eventually found out I had HIV, as they inevitably would as one day I would be lying in a hospital bed covered in Kaposi's sarcoma and all would be revealed. This isolated me from people. Everything around me was impermanent so why get attached?

24. I have never really been able to completely open up to anyone. I have had a few relationship but they never lasted. My current relationship has had its challenges. We have survived 18 years until now, but my difficulties with personal contact remain. I am unable to be loved in any physical sense, I don't like to be touched, it is a challenge for me. Although we have been together so long we have not had sexual contact in 16 of those 18 years as it scares me. It has brought up many difficulties for my partners over the years but we have adapted to a life full of love for each other. I have period of depression GRO-C GRO-C GRO-C Mentally, socially and physically life is a challenge.
25. Today, 30 years later, I am still here and, although thankful to be alive, I have had to live life year by year. I have not been able to buy a home or get life insurance. There has been no point in saving for a pension as there is no point in saving except for my funeral.
26. Now it seems I may have a future. I am told I could live to an old age, but gone are the opportunities for me to prepare for retirement and old age: the investment opportunities in life have passed me by, my life has passed me by. I am told HIV is no longer considered a terminal disease. That is the official line, but if I miss a dose of my medication it will fail. If no other treatment works then the HIV will take over and I will die, so it sounds terminal to me. I go on, step by step, still dragging my feet with one foot in the grave.

Section 6. Treatment/Care/Support

27. I have never experienced any difficulties or obstacles in accessing treatment at the Kobler Centre. I do not believe there were any treatments that I ought to have received but did not. I do not believe that my infected status has ever affected the medical or dental care I have received.
28. I was offered counselling and psychological support in consequence of my infection from the Kobler Centre.

Section 7. Financial Assistance

29. I heard about the possibility of infection with HIV through contaminated blood in a report on the BBC in November 2017. I then looked into the probability of my infection being caused by contaminated blood and, in doing my research, I came across the then Eileen Trust, which got my attention as my mother's name was Eileen. Through further research I learnt about the funding which later became the EIBSS.
30. I have made an application for the EIBSS but this has been turned down. I am currently appealing against it.
31. I believe my application was turned down because I have been unable to produce evidence of the blood transfusion and blood products I received in 1985. I have applied for both my GP records and my hospital records. Charing Cross Hospital have told me my records have been destroyed and they hold no records going back to 1985.
32. I have managed to access my GP records (WITN1862002) and these do demonstrate, in a few lines, that I attended hospital for a tonsillectomy. The records for 1984 to 1989 note as follows: on 30 March 1984, 'lipoma of

abdominal wall'; on 3 April 1984, 'lump as above – wants it removed'; on 1 June 1984, 'chest pain – told muscular + related to the fact some [illegible] in the family has [illegible]. Has now changed his name to Gene Portouche → Special Clinic.'; on 1 July 1985, 'Proxy. Has been in Charing X Hospital with severe tonsillitis [illegible]. Awaiting tonsillectomy.'; on 8 August 1986, 'PH of tonsillectomy July 1985 – because of frequent throat infection + a quinsy [...].'

33. I also applied for records from Torbay and South Devon NHS Foundation Trust and was told that the only information they hold for me is a record confirming I attended A&E on 10 June 1984 (WITN1862003).
34. I submitted these medical records to the EIBSS in support of my failed application. The EIBSS, in their rejection letter (WITN1862004), stated as follows:

'We have considered your application for HIV payments and I regret to inform you that your application has been unsuccessful.'

Applications can only be authorised where there is evidence that, on the balance of probabilities, the HIV infection was as a direct result of receiving blood, blood products or tissue transfer. The supporting medical information submitted in your application did not provide sufficient evidence that this is the case.

The EIBSS medical assessors were therefore unable to conclude that your HIV infection was as a direct result of the receipt of an NHS transfusion following your tonsillectomy in 1985, as there was no documented evidence that this was the case.

Also, the most common route of transmission of HIV is through having anal or vaginal sex without barrier protection. It is documented in the GP notes from 1984 that you were referred to 'special clinic' i.e. GUM

clinic; this would most commonly occur due to a result of high risk sexual activity.'

35. The EIBSS has interpreted the 'special clinic' referred to in my GP records in 1984 as a GUM clinic and concluded, it appears, that anal intercourse was probably the likeliest cause of my infection. I am devastated by the conclusions they have reached and the discriminatory attitude that this demonstrates. In 1984 I was in a heterosexual relationship and, at that time, I had never been to or heard of a GUM or STD clinic. The 'special clinic' referred to in my GP notes relates to a visit to the A&E department for lipoma (cyst) removal in 1984.
36. In order to respond to the EIBSS, I have asked my treating hospital at the time, Torbay and South Devon NHS Foundation Trust, to confirm (i) there is no evidence of me having visited a GUM clinic during my time in Torbay and (ii) that to provide any information that they have about the removal of the lipoma in a surgical clinic in Paignton. They have responded to say, 'at the present time we have not located any information for the period 1982 to 1986', but that they were continuing to check their archiving system. Given Torbay Hospital was able to provide some records for me (see paragraph 31 above) I hope the EIBSS will accept this response as evidence that I had never been to an STD clinic prior to 1984.
37. I am still awaiting an appeal date for the EIBSS.

Section 8. Other Issues

38. I am very concerned about the gaps in my medical records. The tonsillectomy is the only major operation I have had in my life. My hospital records show my whole medical history with the exception of the period when I was infected at Charing Cross Hospital in 1985. I have tried everything to obtain my records, including trying to locate microfiche, but am told the records no longer exist.

Strangely, there are records for when I attended hospital in 1984 for lipoma removal and the removal of ingrown toenail, but the records for the period of June and July 1985 have disappeared, except for a few notes in my GP records. Without these few GP records I would never have been able to demonstrate I had even attended the hospital or had the operation.

39. It has been very difficult to obtain my records and I am still fighting to do so. It has taken me over a year to go through the process of requesting my records. I do not understand why the records for a major operation including blood transfusion and use of coagulants have disappeared. I believe there are records out there somewhere to prove my case. There must be surgical records for the operation, records at the blood bank, hospital batch numbers for the bloods received by the hospital and distributed to patients, nurse notes from the ward, from the anaesthetist, etc, but I have been given nothing.
40. I believe these records should be given to me and that the onus should be on the NHS to prove that I was not infected by the blood transfusion given, rather than the other way round.
41. I hope the Inquiry is able to get to the truth of what has happened.

Statement of Truth

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

Signed

GRO-C

Dated 14 February 2019