

Witness Name: Robert Kennedy

Statement No. WITN0944001

Dated: 16/07/2019

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF ROBERT KENNEDY**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 May 2019.

I, Robert Kennedy, will say as follows: -

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

1. My name is Robert Kennedy. My date of birth is GRO-C 1958 and my address is GRO-C I am retired and live with my second wife, Sandra. (See WITN3417001). I am a haemophiliac who was born with Von Willebrand's disease and I intend to speak about my infection with Hepatitis C.
2. I confirm that I do not have legal representation and do not require anonymity.

#### **Section 2. How Infected**

3. In 2000, I was involved in a very serious car crash when I was working for a paint company, Autopaint International. I sustained injuries that resulted in the loss of my spleen and half of my stomach
4. After the car crash, I was told I had hepatitis by the surgeon, at Huddersfield Hospital. The doctor came into my room and sat down to let me know how the surgery had gone. He informed me that they had found a problem with my blood test and that it showed I had hepatitis. He asked me if it ran in the family or if I had any idea how I had been infected. It was all going in one ear and out the other. I thought it was fatal and that it was going to turn into AIDS. I just thought that I was going to die. I didn't know that there were different strains of hepatitis. With my luck, I thought I would get HIV. Dr said that I had to have further tests to find out what strain it was.
5. Although I was diagnosed with hepatitis in the hospital, the actual strain, Hepatitis C, wasn't diagnosed until a month later by the Haematologist at Huddersfield Hospital. I was notified by letter. They asked me to come and see them and asked me how I thought I had contracted it. I didn't have any idea.
6. I was asked if I had ever used intravenous drugs and then followed the usual questions about unprotected sex, but I have never done drugs and was positive I couldn't have contracted it from sex. Also, I have never had a tattoo. They then asked me about whether I had ever had a blood transfusion and that is when it clicked.
7. When I was 18 months old, I suffered a severe bleed to my foot (I can't remember which one) and received a pint of blood by transfusion. This was at Dryburn Hospital
8. To my knowledge, I didn't have any other blood transfusions between the one I had when I was 18 months old and then in 2000 after the car crash.

9. I have only been treated with factor products about four or five times in my life, usually when I have had dental work. I used to be treated with Factor VIII but they have different products now.
10. My Mum was very careful. I was her only child and she used to wrap me in cotton wool. She wouldn't even let me go out and play that much as she was scared I would cut myself. As a result, I didn't have many bleeds and so didn't have many treatments. When I was diagnosed with HCV I asked my Mum if I had had any blood transfusions when I was young but she could not recall anything like that happening. However, I do remember her telling me about it and I think with her age she had just forgotten.
11. I was given no information by either the Haematologist or Huddersfield Hospital about the condition itself or how to manage it, nor about any precautions to take around others. I was just told that it could be passed on through sex and bodily fluids.

### Section 3. Other Infections

12. I do not believe that I have contracted any other infections as a result of being given infected blood, apart from what I believed to be Hepatitis C.

### Section 4. Consent

13. I have always consented to the tests and treatment that I have had for HCV. Albeit, I was not aware that I was being tested for it at the time when I was operated on. Before I underwent my treatment in 2017, we signed up for a drug trial. They sat us down and explained what would happen. My blood test results would go to a lab for examination as well as to the specialist, but we agreed to be part of that and signed a piece of paper.

14. I don't believe that I have ever been denied any treatment that was available at the time and as I will explain actually deferred my treatment for some time.

#### Section 5. Impact

15. Obviously, I didn't know that I had been living with HCV for all of my life until I was diagnosed in 2000. All I knew was that I kept feeling depressed. I was tired and very short tempered. This was almost constant. I was always anaemic and iron deficient, and I couldn't keep weight on.
16. I had depression as a teenager. At the time, I just thought it was me and a part of being a teenager and growing up but to this day I still suffer from this. I have never been treated for it, either by way of drugs or counselling. You feel very fatigued, weak and very stressed, but you don't know why and that gets you down. I was simply told to eat all the greens I could but never had any treatment for iron deficiency.
17. I was diagnosed with Von Willebrand's from birth. My Mum was aware that it could be passed on. However, the Von Willebrand's didn't prevent me from working. I was a panel beater by trade. When I was diagnosed with HCV, I was running a garage with my wife. I would repair and spray cars, but I had to stop because I lost my upper body strength. I was just too exhausted all the time and couldn't keep up.
18. As a panel beater, I would have been on about £40,000 per annum and I lost that regular income as an effect of HCV.
19. It has had no impact on me educationally as I was diagnosed long after I left school. However, it has prevented me from running my business, something I had always wanted to do.

20. I went to work elsewhere, at Bristol Street Motors, after giving up my own business but again had to leave because of fatigue, but mainly because of stigma that comes with the infection. As soon as I informed other people, such as my boss and colleagues, that I had HCV, I soon realised that people didn't want to work with me. I was the victim of a whispering campaign and life was made generally difficult for me until I left. They just didn't want to know me. I also experienced this to an extent from people I came across and told when I was running my own business.
21. I am a bass player in a local band, and used to play with Prefab Sprout who went on to do world tours and used to pack out arenas. I've played at the Hammersmith Odeon. The HCV has actually had a huge impact on my musical life. Previously, I could do about 5 gigs a week, but now I can only manage 2 and it's a huge effort. I had given up music completely for three years before I met Sandra because I couldn't cope with it.
22. Telling people that I was infected with HCV meant that I lost a lot of what I thought at the time, were friends but it hasn't caused any problems with my family. However, my wife has lost her opportunity to continue working as she has had to look after me. You don't realise how much of a sacrifice those around you have to make. I would be lost without her help and support on a daily basis.
23. It hasn't ever affected my Mum though. I left home when I was 16 or 17 and got on with my own life, and we never really spoke much about it. Mum was living in GRO-C and I was living in GRO-C when I got the HCV diagnosis. She didn't come and visit me as she wasn't well herself so her doctors advised her not to travel for her own health.

24. I couldn't get life insurance until I was over 60 at which point I no longer had to answer a medical question.
25. Travel insurance was £800/900 just to go to France for a week, which would be more than the holiday cost so we had to travel without it. Now that I have cleared the virus, I don't have to declare it so it is no longer a problem.
26. The HCV has also affected our ability to get away as much as we would like to. The fatigue means that I am often unable to do much and any outing require a fair bit of planning and organisation.
27. I did worry about the possibility that my children may have been at risk whilst growing up but they have all been checked and are fine.

#### Section 6. Treatment/Care/Support

28. I had my first treatment at Bradford Hospital in around 2004/2005. I had a couple of injections in my shoulder to take the virus down but I can't remember the name of the drug. The side effects I experienced from the injections included dizziness and feeling nauseous. I had the same injections at the GP when we got to GRO-C. I wasn't bedridden, but I wasn't too good either.
29. My liver was showing early signs of damage but there was no scarring. Having spoken with my wife, I decided not to undergo therapy as it was going to be too invasive. The way it was explained to me was that it would be a bit like having chemotherapy. I was told it would knock me out for three days and I would need 24-hour care when I was in bed so my wife and I decided not to accept this at the time.
30. Having discussed it with the consultant, we agreed that he would monitor my condition and when it was absolutely necessary I would take the treatment. I realised that if I embarked on a course of the

treatment, I wouldn't be able to play bass in my band any longer, which was one of the reasons I decided to delay it.

31. I moved to GRO-C in 2010 and wasn't working. I had constant aches and pain, and was on oxygen for cluster headaches. It took nearly a year for me to see a specialist or anyone that wasn't my GP. Finally, I started to see Dr Bethan Myers who was my haemophilia specialist and Dr Aravamuthan Sreedharan for the HCV. I was offered the invasive treatment again and once more we declined. They agreed to continue monitoring me as before and started sending me for liver function tests.
32. In 2017, Dr Sreedharan told me he had put me forward for this new treatment that was available and I had been accepted. I had to take a course of tablets for 8-12 weeks and within 6 weeks it had cured the virus.
33. Incidentally, I have seen my medical records and it is always marked as hazard for HCV. It says "Infectious" on it and has a red sticker.
34. It clears the virus but it doesn't clear the problems that it causes so I still have aches and pains and still suffer from anxiety and depression. Also, the virus has damaged my immune system so much so that I still need iron and mineral supplements. I still suffer from chronic fatigue and I doze off and on continually during the day.
35. When I was first diagnosed, I was never offered psychological counselling or any education about my condition and how to deal with it. In the end, I did get psychological help as a result of Sandra badgering me and fighting my case with the Health Authorities. Eventually, I saw a psychologist and a psychiatrist when we were living in Huddersfield and it made a big difference. But when we moved to GRO-C, they said I didn't need it. Sandra tried to get the same sort of help for me as before but it was a different Health Authority area and they just were not interested.

36. With regard to other healthcare, I did have problems with dental treatment when living in GRO-C and was often sent to the hospital for the work to be carried out as my local dentist would not touch me. I think they were also scared of the possible bleeding. My current dentist is very good and I have had no problems.

#### Section 7. Financial Assistance

37. I found out about the Skipton Fund from the specialist in Bradford who advised me to apply. I applied in 2008. I was told that I had to send my medical records to them in order to get payment. It was so hard to get all the records together that my application wasn't completed until 2012. By then, it was under the English Infected Blood Support Scheme and I received the Stage 1 payment for £20,000. I also now get an income of around £630 per month in total from that organisation. However, they never returned my medical records.
38. During my earlier treatments we never got any compensation for travelling to and from medical appointments. Often, they were many miles away from where we lived. There was no assistance for travel or for hotels that were often required.

#### Section 8. Other Issues

39. I am glad it's come out now about the contaminated blood scandal, as a result of the Inquiry. It feels that it was swept under the carpet for so long by the Authorities. I believe that it effects around one in nine people. it's unfortunate how so many people have had to suffer in silence and how many have died. It's a crippling disease as well, with the depression coupled with the level of fatigue that it brings to your daily life. Then there's the physical side of going for the



injections for many. They're painful but you have to do it and it's a long road to recovery.

40. I confirm that following explanation I have signed a consent form in relation to the use of my statement, on the basis that it is submitted along with my signed witness statement.

**Statement of Truth**

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

Signed

GRO-C

Dated

16/07/2019