Witness Name: Sandra Kennedy
Statement No.: WITN3417001
Dated: 16-07-2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SANDRA KENNEDY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 May 2019.

I, Sandra Kennedy, will say as follows: -

Section 1. Introduction

1. My name is Sandra Kennedy. My date of birth is GRO-C 1957 and my address is known to the Inquiry. I am the wife of Robert Kennedy. (See WITN0944001). I intend to speak about Robert's infection with Hepatitis C and how it has affected our lives together.

2. I confirm that I do not have legal representation and do not require anonymity.

Section 2. How Affected

3. My husband, Rob, was born with Von Willebrand's disease.

4. In 2000 he was involved in a very serious car accident while at work. He lost his spleen and half his stomach and the consequent surgery meant that he required a blood transfusion at Huddersfield Hospital, West Yorkshire After the surgery, The Surgeon came to see Rob to tell him that he they had found a problem with his blood test and that he had hepatitis.

5. Rob was referred to a haematologist at Huddersfield Hospital to find out what strain of hepatitis he had, and one month after the surgery they sent him a letter to say that he had Hepatitis C and to make an appointment to come and see them.

6. They asked Rob if had taken intravenous drugs and about his sex life or if he had any idea how he had contracted the virus, but he had no idea. I remember when I met Rob he always used to look as though he had been painted with a gold paintbrush. He looked jaundiced all the time. The whites of his eyes were pale yellow and he kept falling asleep. If you left him for 5 minutes he'd fall asleep. Now we know that those are symptoms of Hepatitis C, but at the time neither of us knew.

7. The doctor asked if he had ever had a blood transfusion and we spoke to his Mum and then it clicked. When Rob was 18 months, he had a severe bleed in one of his feet and was taken to Dryburn hospital county Durham where he had a blood transfusion. I've seen his medical record and it states he had 1 pint of blood. He hasn't had any blood transfusions between then and the car crash so it must have been then that he was infected.

8. At that meeting they didn't give us any information about how to manage the virus or precautions to take around others, but asked Rob if he wanted to be considered for a course of treatment. Following a discussion, we said no to the offer at that time.

Section 3. Other Infections

9. As far as I am aware, Rob has not contracted any other infections as a result of being given infected blood, apart from what I believed to be Hepatitis C.

Section 4. Consent

10. Rob has always consented to the treatment that he received for his HCV. Before his treatment in 2017, we signed up for a drug trial, but they sat us down and explained that they were going to send his results off to a lab as well as to the specialist. But we agreed to that and he signed a piece of paper.

Section 5. Impact

11. I noticed that there was something wrong psychologically with Rob because he was locking himself in the bedroom and crying and he wouldn't get out of bed. I told him there was something wrong with him and that we should go and see the doctor, but he didn't want to go because he thought that they would laugh at him. I said that they wouldn't laugh at him as he was with me and if it came to it I would make them understand. I believe that Rob has been too accepting in the past of what he has been told by the medical profession. Eventually a doctor listened to us and Rob started seeing a psychiatrist and a psychologist, which prompted a big improvement in his condition and well-being.

12. Physically, he was still very tired. If you left him alone for 5 minutes he would dose off. He is a bassist in a band but he can't lift his own gear so I have to do all that with the lads. Rob had given up the music completely for about 3 years until he met me as he just wasn't physically capable of coping with the exertion.

13. When we moved to Huddersfield, we found the dentist that we had registered with wouldn't touch him and sent him to the hospital for even the most minor treatment, but that was more than likely related to his haemophilia and their fear of bleeding.

14. I do remember though, when we were living in Halifax, he had a nose bleed and it wouldn't stop bleeding. He was losing a lot of blood so we got an ambulance to the hospital. At the hospital, the nurses wouldn't touch him. Whenever we went to the hospital, I would say out loud that he had HCV so that people would make sure to wear gloves and take necessary precautions. I remember that the doctor said to this young nurse to hold his nose and she wouldn't hold it because he had HCV, and I had to hold it.

15. When Rob was diagnosed with HCV, we had a garage with people working for us. Rob was a panel beater by trade, and he would spray and repair the cars. It was our own business but we lost it as he couldn't repair the vehicles any longer because he lost his upper body strength. Rob became so tired that he couldn't physically cope with the demands of the business. We thought we would give it a go as opposed to going on the dole but in the end, it was just too much for him. I couldn't run it on my own, so we had to pack it up. Autotex, Huddersfield was the name of the business and we lost it all due in the main to the effects of the HCV.

16. The people he worked with also made his life hell when they found out he had HCV. When they went on break and had a cup of tea, if Rob had used the cup they didn't want it. They treated me the same way by association.

17. The Job Centre were the worst. We went to the Job Centre because he didn't have a job and when we told them about the virus, they told us not to tell potential employers. They said if we didn't mention it, then they wouldn't know!

18. When our neighbours in Huddersfield found out that Rob had HCV, they gave us a hell of a life. They would shout at you in the street, which would in turn make you reluctant to leave the house. Even in your own garden people would shout over at you making derogatory remarks. This was one of the reasons that we moved to Lincoln. We used to speak daily before as they were our neighbours, but when they found out about the HCV, a whispering campaign started. It seemed they would do anything to try and get shot of you.

19. It's completely different since we moved to Lincoln. We told our friends in advance and they were fine. They take him out and if Rob has one of his headaches, which make him go blind, they will take him home and make sure he's alright. This is another symptom of the HCV and its treatment. Also, Rob can talk to his mates about the HCV and that helps a lot as he doesn't bottle everything up.

20. I lost my opportunity to continue working to look after Rob. I used to work as a care assistant, in factories, and then in the garage, but I had to stop. There were times when he didn't want to get out of bed, wash, eat, and I had to push him, dress him, make him eat. Watching Rob, its is as if the virus slowly sucks the life out of you – if you let it.

21. Rob's HCV hasn't caused any splits in the family though or trouble with our kids. Our daughter, Lisa, was a bit worried that it could be passed on to her kids through the genes but once she found out that wasn't the case, she was fine, GRO-C There have never been any problems with our son either.

Section 6. Treatment/Care/Support

22. In 2004/2005, Rob had his first treatment at Bradford Hospital. He had a couple of injections in his arm to take the virus down but I can't remember what the name of the drug was. This was the first treatment we had ever been offered.

23. We kept going back for appointments every three months and they offered us tablets as part of the treatment, but the consultant said that it would knock Rob off his feet and he would need constant care so we decided against it at the time. There were certain things that he could do and certain things that he couldn't do, but if he did the treatment, he wouldn't have been able to do anything.

24. We agreed with the consultant that they would take blood samples and continue to monitor Rob.

25. We then moved to Lincoln in 2010 and it took nearly a year to get Rob back under a specialist so he wasn't seeing anyone apart from the GP. In 2011, he started seeing Doctor Bethan Myers for his haemophilia and Dr Aravamuthan Sreedharan for the HCV.

26. They offered us this same invasive treatment again and again we said "no". Dr Sreedharan gave us his phone number and said to go home and think about the treatment and then to give him a call when we had decided. Our thinking was that if Rob's bedridden – as that is what we were told the treatment would do to him - that is taking his life away so we wanted to delay that as much as possible. We knew he would need the treatment one day, but we chose to hang on.

27. They agreed to continue to monitor Rob and that's when they started sending him for liver function tests at Nottingham Hospital.

28. At some point in 2017, Dr Sreedharan said that he had put Rob forward for this new treatment that had become available and he had been accepted. It was an 8-12-week course. At the end of the course, they did three blood tests on him for Hepatitis C and because the results showed less than twelve, they said that he was clear and did not have to go back for any more liver function tests. Since then, Rob has just continued to see Dr Myers for his Von Willebrand's.

29. I believe in my heart of hearts, we were told everything and offered all available treatments and that nothing was held back from us.

30. When we were living in Huddersfield, I was able to persuade the doctor that Rob needed to see a psychiatrist and a psychologist, and he made a big improvement. Psychological help has never been offered. It is something we have fought for in the past and continue to do so.

31. But when we moved to Lincoln, he was no longer allowed that and has never been able to have that since. Even though he was receiving it before and it was helping him, it's under a different NHS trust. They told us that he didn't need to see a psychiatrist or a psychologist because they couldn't do anything that the doctors couldn't do! They told us that they could prescribe him tablets but it was the other exercises that he was doing, as opposed to the tablets that were so useful. For instance, they would get him to write down things that were bothering and him then tear up the sheet of paper and I think that he found that helpful. He still takes prescribed anti-depressants.

32. He called up Steps 2 Change three years ago, but he is still on the waiting list despite his obvious need.

33. I have never been offered any psychological help despite having had to watch Rob go through this. I suffer from depression, but just take my tablets and get on with it. Rob's psychiatrist from when we were living in Huddersfield would tell me that I needed help as well, but when we moved to Lincoln it all changed. I have asked for help as well and they just tell me to keep taking the pills. Rob is still using the medication and has been on it for years. Sometimes though, I thing you can be on the pills for too long and you become immune to them and they stop working. Rob takes about 15 pills a day to stay alive and just get through the day. These are a mixture of different medications.

Section 7. Financial Assistance

34. We were told about the Skipton Fund by Rob's specialist in Bradford Hospital who advised us to apply. He explained about how you got funding and said that Rob would have to provide a blood test. We applied for it in 2008 and it was only completed in 2012 because it was so hard to get all the records. They asked us for £10 or £20 every time we asked a different place for his records. The difficulty was getting the paperwork together.

35. We received the Stage 1 payment of £20,000 in 2012 but it wasn't until 2019 that we knew that we could get the monthly payments as well. Also, nobody had told us that he could have claimed for bus fares. We had always thought that the £20,000 was it. I think we found out from the Infected Blood Inquiry. We are now getting 2 monthly payments of £330 and £300 per month and then a winter fuel payment of £500. Rob has also received a letter to say that the payment has gone up and that he will receive a back payment in July.

36. They are going to do a benefit check on us and will then back date the payments as far as they can, but that they will only be able to go back so far. As a result, we will have lost out on a chunk of money. However, as we thought that it was just the £20,000 we think that it is fantastic to get this support.

Section 8. Other Issues

37. It's one of those things which never should have happened and something should have been done about it a long time before now. The impact that it has had on widows who have lost husbands or wives and on kids who have lost mums and dads. It is terrible and shouldn't have happened.

38. It makes you lose faith in the NHS because if they can cover up something as big as this, it makes you wonder what else they cover up. They are still trying to push it under the carpet.

39. People need to know what is going on around them and what is happening to them. There is nothing worse than when you don't know what is wrong with you. Once you know, you can get on with your own life and deal with it, but if you don't know then it scares the life out of you.

Statement of Truth

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

Signed GRO-C

Dated 16/01/2019