

Witness Name: Raymond Keen

Statement No.: WITN2638001

Exhibits: [WITN2638002 –
WITN2638005]

Dated: 7 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RAYMOND KEEN

Section 1. Introduction

1. I, Raymond Keen will say as follows. My date of birth is GRO-C 1949. My address is known to the Inquiry.

Section 2. How infected

2. In 1984 I was diagnosed with Cardiomyopathy which became Myocarditis, my heart was swelling and they could not stop it. I had been suffering with chest pain for months and had been getting out of breath just by talking. I had been fit and healthy until that year. I was informed that my illness was caused by a viral infection that I had picked up when I was on holiday in Majorca earlier that year. I had never been out of the country before and when I came back I was

covered head to toe in mosquito bites, the doctors said that the mosquitoes could have caused the virus.

3. My symptoms got worse and worse. I was eventually admitted to Northwick Park Hospital in September 1984. I spent most of the next two years in hospital. Northwick Park Hospital had a kind of experimental unit attached to it at that time. I was treated with Antilymphocyte Globulin or ALG which is made from horse serum that they got from Germany. I believe this was in 1985. I was locked away in a side room whilst having this treatment because it wipes out your immune system completely. The guys that I was in hospital with thought it was funny that I was having this serum from horses and used to make lots of jokes about it. They would stick pictures of anything related to horses on the windows of my room to cheer me up.
4. I was told that the ALG was the only treatment that would save my life. I could not have a heart transplant because I have a very rare blood group. I now know that I am one of the only people that survived the ALG treatment. Many years later I was contacted and asked to take part of a study but was unfortunately too unwell to be involved.
5. I found out later that I was given blood products at the same time as being given the ALG. I do not know what kind of blood products I was given. I have never had a blood transfusion or been given blood products at any other time.
6. I was never informed of any risks of being exposed to an infection via the ALG.
7. The ALG stopped my heart from swelling and eventually I was fully discharged from hospital.
8. After being discharged I still felt breathless, I was very achy and tired and had constant diarrhoea. The doctors had told me that my myocarditis had improved and so I could not understand why I still felt so unwell.

9. I was a regular blood donor before I was admitted to Northwick Park Hospital. Because I have a rare blood group I would give platelets and a bag of blood. I had helped to save my father-in-law from cancer when he needed a blood transfusion. I was three donations off getting my Wedgewood for 100 donations. The last time that I gave blood was on 15 June 1984.
10. In early 1987 I was told by the National Blood Service that I had tested positive for Hepatitis B. I went to see my GP and was referred to see a liver specialist in London. This specialist told me that I had chronic Hepatitis B. He told me that I had to be careful not to have blood to blood contact with anybody and that if I ever had sex again I had to be very careful because I could pass it to my wife. This doctor did provide me with quite a bit of information about hepatitis B, he laid it all out for me.
11. I was stunned. I could not understand where I had got this infection from. My GP referred me to another specialist. I do not remember who this was or which hospital I attended to see him. This information is not included in my GP records. I remember that I had to drive quite a way to get there. When I sat down with him, this doctor told me that he had been through my notes and had found out that I had been given blood products at the same time as being given the ALG. He said that this is where the infection had come from but he added that without the drug I would have been dead. He advised me to leave it there and to not take things further. I think that he meant not to complain or take any action against the hospital. I did not realise then the impact that the hepatitis B would have on my life.

Section 3. Other Infections

12. I am not aware of receiving any other infections as a result of being given contaminated blood products.

Section 4. Consent

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

Section 5. Impact

14. A few months after I was discharged from hospital our house was repossessed. I felt that I had no choice but to go back to work. I carried on working for as long as I could but I would get so tired and achy and I did not understand why. I worked for a couple of years to get us back on our feet and we managed to get enough money together to put a deposit down on the house that we are in now. But after that I had to give work up completely, I was aching all over and I felt as if I just could not do anything.
15. Not working and just sitting in a chair doing nothing destroyed me. I went from being a workaholic, working seven days a week, to being confined to an armchair. A few years after my diagnosis I started volunteering as a driver taking elderly people to hospital. I still do this when I feel well enough.
16. I got so fed up as a result of being stuck indoors; when you are working you are speaking to people all the time, when this was taken away from me the depression set in. I was trying to find ways of killing myself which would make it quick and get it over and done with. I checked our insurance documents and found that if I committed suicide the insurers would not pay out to my family. I felt trapped, as if I could not get out of this situation. If it wasn't for my children or grandchildren I would have taken my life a long time ago. I have been angry for years and years about what has been done to me, one of the worst things is that I cannot do anything about it.
17. Around six years ago I got very ill and turned bright yellow. I had a liver biopsy at the Kent & Canterbury Hospital. This procedure was really painful; I had to lie

on my side and could not move. I could have bled to death; there are times when I wish I had. The doctors told me that my liver was so damaged that it was going to shut down. They asked me whether I wanted to die at home or in hospital. I told them that I wanted to go home.

18. I had a party, a wake to say goodbye to all of my friends and family. But I am still here, now they take the mick out of me and say "what some people would do for a bit of sympathy!"
19. I am still here but I am not well at all. I have regular bouts of diarrhoea which can last weeks. It destroys me, I have no energy. I feel constantly tired and achy, my stomach is so swollen that I look as if I am pregnant.
20. In early 1992 they gave me a drug called interferon which I had to inject into myself three times per week. The side effects were horrendous, worse than the symptoms of hepatitis. About an hour after I injected myself I felt like death warmed up, like I had flu a thousand times over. My bones felt as if they were being crushed. I could not do anything. The first time that I took interferon I called my doctor and asked him what was happening to me, he told me that the symptoms that I described were normal.
21. I first took interferon for around four months, however the treatment was not having an effect on the hepatitis B. I stopped the interferon for several months and then started the course again. However a short time after I re-started I just could not take it anymore, I told the doctor that I could not cope and the treatment was stopped. I never had any other treatment to try to clear the hepatitis after that. The treatment was unsuccessful and so I still have hepatitis B.
22. I am not aware of any other treatments that could have been made available to me.

23. When I was diagnosed I was so worried about passing the hepatitis to other members of my family, particularly to my wife. This has caused major problems in our relationship; we have split up so many times over the years. We are together now but there is still no intimacy between us, it is not like a normal marriage.
24. I have nine grandchildren; I have to be so careful around them. I know it is unlikely that I would pass it to them but even that small chance of it happening terrifies me. They all love me to bits but when they come up to kiss me on the lips I turn my head so that they kiss me on the cheek instead. I feel distant from them because I feel that I cannot kiss them. I feel as though there is a barrier around me and that I cannot get close to them. People just don't realise what this infection does to families, there is no normality in life at all. I would not wish this on anyone, not even my worst enemy.
25. I had a friend who I had known since school who totally stayed away from me after I was diagnosed. I found out that he was worried that he would catch hepatitis if I spat in his eye while talking to him. Other friends now don't come anywhere near me and don't want to know me. The hepatitis has taken all of the intimacy out of my life, I just don't want to get close to anyone.
26. Everywhere I go there is a sticker on my notes which states that I have hepatitis B. It's like I am walking around with a banner on me stating "unclean". Hospital staff treat me differently, there is always a feeling in the air that they need to be careful around me.
27. Before I went into hospital with the myocarditis my life was good. I was in my early thirties and had my own company. We had bought our council house and had built an extension out the back. But because of the hepatitis I was not well enough to work as I had before. I ended up losing my business and my house.

28. I worked as much as I could. However I was having so much time off that eventually my employer sent me to see one of their own doctors. I was exhausted and my stomach was really swollen, it was clear that I was very unwell. I did not want to tell them about the hepatitis, I felt so unclean and did not want anyone to know about it. I felt that I had to leave my job because I physically could not continue to work. After that I had no choice but to live off benefits, I hated it.
29. I went from running my own business, earning between £50,000 and £60,000 per year to earning £12,000 to £13,000 per year, and then trying to live off a few hundred pounds per week. We struggled with everything; paying the bills, the mortgage, everything.
30. We had been sold our mortgage by a friend and we thought it was a good deal at the time. But when other interest rates began to fall, ours did not. The housing benefit was not enough to cover the monthly payments and we began to build up mortgage arrears. I tried to explain to the mortgage company that I could not work but they did not listen, they did not want to know. They tried to evict us and then bailiffs arrived, they were looking round my lounge asking me what items I wanted to keep. Eventually my MP stepped in to stop us being evicted and my son managed to borrow some money to pay off the mortgage. We have paid it back to him bit by bit out of our benefits. Having to fight to save this house after we had already lost the first one was terrible. People don't realise what that does to a person.
31. Recently my wife and I started to receive the state pension and the government stopped the benefits that we were receiving before. I have paid very little national insurance because I have been unable to work for so much of my life. As a result I am on a limited pension. We have lost about £400 per month. I don't understand how the government can just take that money away all of a sudden. This has just added to the problems between me and my wife and to my depression.

Section 6. Treatment/Care/Support

32. I have not faced any difficulties or obstacles in obtaining treatment but I am very aware that hospital staff have to be careful when they are taking blood or dealing with any kind of sample from me.
33. I have received counselling in the past. A chap visited me at home and saw me two or three times per week. It helped for a while but the depression always rears its ugly head. I think that my GP would refer me for counselling again if I needed it.

Section 7. Financial Assistance

34. I found out about the financial schemes through the support groups on Facebook. However I have never received any payments or any other financial assistance.

Section 8. Other Issues

35. I have now got to a stage where I feel that someone should pay for what I have been through since being given contaminated blood products. I glossed over it for years and years and did not realise how widespread it was until I joined the support groups on Facebook.
36. In early 2018 I decided to approach a solicitor to take action against Northwick Park Hospital for giving me contaminated blood products. The solicitors applied for my medical records. Once they received them they contacted me to say that it would be difficult to show that I contracted hepatitis B as a result of receiving contaminated blood. It was then that I found out that my records had been doctored.

37. My solicitors sent me extracts of my notes which state that I had contracted hepatitis whilst on holiday in Mallorca in 1984 [WITN2638002]. One letter even states that I informed a psychiatrist that I caught hepatitis by eating a salad [WITN2638003]. I could not believe what I was reading. First of all me and my wife are always really careful when we go on holiday; we don't drink the water or eat anything washed with water and we always make sure the food is piping hot. And more importantly hepatitis B cannot be spread this way, you can only get it through bodily fluids, via infected blood or through sexual contact.
38. I donated platelets and blood twice after I returned from that trip to Mallorca. On 25 May 1984 and on 15 June 1984 I gave 7 bags of platelets and a unit of blood [WITN2638004]. However it was not until I gave blood in 1987, after the ALG treatment, that the blood and transfusion service detected the hepatitis B virus in my blood.
39. The records also say that my wife had hepatitis B and that she caught it at the same time, my wife has never had hepatitis. She was not ill in any way after our holiday in 1984. I have no idea where they got this from and do not understand how they can write this in the records. When I was first diagnosed all those years ago the consultant said that he had looked through all of my records and that the most likely cause of the hepatitis was the blood products that I had been given with the ALG. I believe that this consultant relayed my diagnosis to Northwick Park Hospital and that they have done what they could to cover up what happened.
40. Another letter states that I caught it from a mosquito bite in 1991 [WITN2638004]; this was after I had been diagnosed so this cannot be true. I cannot believe the lies they have put down. I am so angry at the nerve of them changing my notes in this way, I cannot believe that people can just do this and get away with it. When the solicitors said they would look through my records I felt that someone had listened and was going to help me get some compensation for what I have been through, but it was false hope. When they

told me that they could not continue with the case I was devastated. Because of the lies in the records there is nothing they can do.

41. When I instructed Leigh Day to represent me at the Inquiry, they applied to Northwick Park Hospital again for my records. Leigh Day received a letter in response stating that the Trust is unable to supply the records because the retention period has passed and they no longer hold the records. This is very strange because the records were provided to my previous solicitors in 2018. I cannot believe that the records have mysteriously disappeared since then, I think they must have destroyed them all.
42. I have looked for help and additional support but I cannot get it because my records state that I got hepatitis after eating a salad and do not explain that it was because of the ALG. It's like banging your head against a brick wall. It's not about the money, although it would help us with the day to day. I just want someone to pay in some way for the loss and upset they have caused.

Statement of Truth

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

Signed

GRO-C

Dated7 March 2019.....