

Witness Name: Melvin Burton

Statement No.: WITN0666001

Exhibits: N/A

Dated: 24/01/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MELVIN BURTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7 December 2018.

I, Melvin Kenneth William Burton, will say as follows: -

Section 1. Introduction

1. My name is Melvin Burton. My date of birth is GRO-C 1947 and my address is known to the Inquiry. I am a retired watch and jewellery maker and currently live by myself and have done so for my entire adult life. I will come to the reasons why later in my statement.
2. I intend to speak about my infection with the Hepatitis C virus ('HCV'), which I contracted as a result of being given contaminated Factor IX to treat my severe Haemophilia B.
3. In particular, I intend to speak about the nature of my illness, how the illness affected me, the treatment received and the devastating impact it has had on my life.
4. I confirm that I have chosen to not be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. When I was a child I often suffered with bleeds, I was frequently black and blue. The doctors at the time really did not know what was causing my bleeds; at that time in history it was beyond them.
6. As time went on, I was diagnosed with what was known back then as 'Christmas disease'. This is now called severe Haemophilia B. This would have been in the late 1970's. This diagnosis meant that I had to frequently visit hospitals to control my bleeds.
7. I used to haemorrhage severely when I was younger and my knees would swell up. When you get a bleed in a joint the blood has to go somewhere, this forces the joint apart. It's like an old fashioned bottle of milk freezing on your doorstep and when you collect it the silver foil stopper has popped off due to the expansion of the contents.
8. At this time there was no treatment for people with Haemophilia. The pain was unbearable. I decided after several trips to the hospital, when I was able to make my own decisions, that I would have nothing to do with hospitals, I was fed up.
9. In the early 1970's, I accidentally cut my hand with a fluorescent tube. I went to the Cottage hospital at Ripley to seek treatment. They bandaged my hand and I went home. However, blood was starting to seep through the bandage and the bleeding became so severe that I had to go back to the hospital. At this point I told them I had Haemophilia. I was then informed that the hospital was not geared up to deal with me. The doctors at the hospital further told me that they were sure I did not have Haemophilia. Nonetheless, I was required to visit the Derbyshire Royal Infirmary, which is now called the Royal Derby Hospital, albeit it is a new hospital.
10. When I arrived at the Hospital, the doctors did a variety of tests including blood tests. I was informed that I had virtually no Factor 9, it was around 1%. My bleeds were so consistent the doctors used my blood as standard to compare and test other people. I was happy for that to happen. The consultant at the time told me that the hospital

- had a new treatment they could offer me, Factor IX. I was told it would help control my bleeding.
11. After that, I frequently visited the hospital throughout the 1970's whenever I suffered a haemorrhage.
 12. I was often administered Factor IX by a women called GRO-D. Towards the late 1970's or early 1980's, in my early 30's I noticed that things started to change. On several occasions when I went to receive my injection GRO-D could not stop shaking. I remember her saying she did not know why she was shaking. I started to question her; she was a sister, not a nurse. This would entail that she was experienced; she should know was she was doing. I believe she was shaking as she liked me and knew there was something deadly in the treatment. In my opinion it was affecting her, she hated herself for giving the Factor IX to me but she had to.
 13. I recall one occasion in the late 1980's after I had an injection I went to see a friend of mine in Chesterfield. I started the day normally, feeling fine but aware I had to go for my Factor IX injection before I drove to my friends place. As usual I attended the Derbyshire Royal Hospital to receive my injection. I then went onto Chesterfield, which was around 12 miles away.
 14. However, when I got to Chesterfield I started to feel really strange. I told my friend I did not feel well and that I would have to go home. The injections had never affected me like this before. My symptoms made me feel like I was going to pass out. I went very pale and clammy, felt terribly sick and I wanted to vomit. I drove back home which was a real struggle and I went to bed, got up around teatime and started to feel better. I felt as though it was definitely the injection that had made me feel this way.
 15. Once I felt better I rang the hospital and told them that I had been feeling extremely unwell. The next time I went to the hospital, I questioned them about it and GRO-D told me that they had destroyed the whole batch.

16. At a later date, after I had been diagnosed with HCV, GRO-D denied ever saying that the batch had been destroyed, I guess she was following instructions.
17. This process of me visiting the hospital to receive my Factor IX continued, until a doctor named Dr. Mitchell told me I should start injecting myself. I said yes as I did not mind, they told me that they would supply me with all the equipment I needed.
18. One day, I received a phone call from a doctor at the Derbyshire Royal Infirmary Hospital, Dr. McKernan. She said she would like to have a word with me. I was told the hospital would like to do a test for HIV and HCV. I was tested twice, 1985 and 1990.
19. It was not until two years later, when I was around 35 that I was told that I was infected with HCV. When Dr. McKernan told me, I asked her why it had taken two years for me to be informed. She replied by saying that it was my fault, as I did not go to hospital to see her. This was a very lame excuse. They should have called me in immediately to tell me of the infection. This was very irresponsible on their part.
20. I have heard previously, that a lot of people did not get told that they had been infected. At the time I was a normal man leading the life a single young man leads. I needed to know earlier if I was infected. It shocked me to know that I had been going out doing things men do and I was not aware of the consequences, in particular, that I was potentially infecting the partners I had. I was enjoying life at that time. Whereas in reality things were not that good.
21. Dr. McKernan was one of those people that did not show much emotion, she had a glum look on her face when she told me. When I was told the reasons for not being informed I thought they were weak. This was going to shorten my life; it was not satisfactory. She gave me no advice on: following any procedure, how to manage my infection, no psychological advice and no advice on how I should conduct myself with women.
22. After that time I was told that I should see a specialist. A liver specialist put me on Ribavirin and Interferon. This nearly killed me. I used to look in the mirror and not recognise who was in front of me.

My sister told me that I looked like I had died and was still walking around.

23. I was later informed of a new drug that came from America and was asked to go on it. The American drug consisted of three small tablets: a pink one, a white one and a green one. I was often told how expensive these drugs were. I was on the course of drugs for six months and was told I had cleared the virus. However, the damage done was irreversible. I now do 6 month check ups. I get quite a lot of pain from my liver and I asked the hospital if there is anything they can do and I am told that there is little they can do to help me. I sometimes get a sharp spasm in my side. There is nothing I can do about it. I just live with this now. I am told that I can get a liver transplant. I do not at my age want an operation of that magnitude. I have come to terms with the damage that has been done to me.
24. Currently for my bleeds I am sent drugs that I keep in a special fridge. I use a drug called BeneFIX that helps the blood to clot. Previously, I was given Replenine.
25. I am upset that I was infected with HCV. I was struggling with Haemophilia anyway but to get HCV on top of that seems a bit cruel. An opinion from a doctor in Scotland informed me it could have been the first injection I had that was the injection to infect me. It was obviously one of them. I often wonder if it was the time I felt so ill and the hospital destroyed the batch, I will never know for sure.
26. When I recently spoke to my doctor, Angela McKernan she said to me that I should know it was the blood product that had infected me.

Section 3. Other Infections

27. I do not believe that as a result of being given infected blood products I have contracted any infection other than the HCV. Although, I was told in 2006 that I was at risk of getting variant Creutzfeldt-Jakob disease ('vCJD'), as a result of being given infected Factor IX products.

Section 4. Consent

28. I have been asked if I believe that I have ever been treated or tested without my knowledge or consent and the answer is no, I have always consented to the treatments.
29. However, I do believe that I was given treatment without sufficient knowledge surrounding the products I was given. It is very sad, blood was imported from drug addicts and prisons, I was never ever asked if it was alright to receive these products made from god knows what. I was never asked for my permission to do any of this, it was just given to me. I believe that as Haemophiliacs we were being treated as lab rats.

Section 5. Impact

30. Being infected with HCV has given me and does still give me various mental and physical problems. I used to get nosebleeds; I remember one time I went to a club in Ripley and my nose started pouring with blood. I had to stand there with a towel round my nose. I used to feel so embarrassed. I was tired, lethargic and sick all the time. I used to be a bit pale. My concentration levels were also slightly off. Sometimes, I used to have days where I was in a fog and it felt like I could not see. I had a few days where I could not express myself; I used to put it out my mind. When I did not know that I was infected, I put it down to my Haemophilia or simply having 'off days'
31. The news of my infection made me very sad. I was used to living a normal life and once I was infected it was impossible to carry on living that life. It destroyed my life, that's a fact. It stopped me from seeing women. I never went near women again after I had found out about my infection. I did not get married because of this infection; I thought to myself it is not fair on the female. I might well have been married with 3 or 4 kids and a family to care for me, as I grow older.

32. Mentally, the Ribavirin and Interferon gave me strange side effects. I used to love tomatoes and now I can't stand them. My skin felt funny, like it was prickly and strange. I could have argument with anyone; I was so charge up mentally. People would often say that I frightened them because I was so angry. It was a definitely an effect of the treatment. My consultant had told me I had the worst side effects out of anyone they had seen. Once I was off the drug treatment It took me around 6 weeks to feel normal again.
33. My infection also caused me to become socially reclusive. I did not go out for 6 months after I had found out. I had little contact with anyone else; it was depressing as I had been used to going out.
34. When I was first told about my infection it led me to depression. However, I have had to come to terms with it. I just had to accept that this was my life now or it would destroy me. I decided it would be best if I let it drift over my head.
35. HCV has led to further serious medical conditions. When I was trying to clear the virus I went to see a nurse who told me that the treatment had been successful. However, further tests confirmed that this was not the case, the virus had not cleared, It had come back again even more aggressive. I was then informed that I had stage-two cirrhosis. This was caused by the virus and caused me a lot of pain.
36. In relation to my infected status impacting my treatment, I have found it near impossible to visit the dentist. My local dentist on Derby road would have nothing to do with me because of my infection. They had signs up outside their practice surrounding the topic of HCV. I stopped going, as I did not want to tell them and deal with the embarrassment.
37. There is a lot of stigma associated with having HCV. I did not want to tell anyone about my infected status. People would think if I touched them it would give them a disease. Under normal circumstances you would associate HCV with prostitutes, drug addicts and homosexuals, I am neither of those things. I got the stigma because of my disease, which was given to me through infected products. I only told my family and not my friends about my infection. I felt as though they might not be my friends anymore if they found out.

38. Due to the Haemophilia, my school days were severely interrupted. My education suffered and consequently I had to go to Portland Training College for disabled people to boost my understanding of maths. I had always enjoyed making things and took great delight in making something out of nothing. As a watchmaker and being into making jewellery I found I was interested in intricate things. When I first worked at H.Samuel they let me go on day release to Derby College of Art. I got into jewellery there.
39. When I was put on Ribavirin and Interferon, I became extremely ill. I kept working as long as I could but it got to the point where I could not work any longer.
40. The effect on my financial income was far-reaching. I had to rely on various ex-gratia payments and benefits, which was not easy. I am currently being paid in monthly instalments; I would like to be offered a lump sum, which would provide me with better financial options such as the purchase of my own house.
41. The money I received is simply not enough for the damage that has been caused to me.

Section 6. Treatment/Care/Support

42. I can confirm that in the past I have never been offered psychological support or made aware of such support in relation to my infection.
43. I can confirm that during my interview with the inquiry, I have been informed about the access to the support mechanism that the British Red Cross provide. This is the first time I have been offered this type of support.

Section 7. Financial Assistance

44. In 2004, I found out about the Skipton fund through advertising I had seen. I sent off for the form and filled it in. Straight away I was awarded stage 1 in August 2004. This gave me £20,000.

45. One day I went to see my liver consultant, Dr Austin. I asked him if I had cirrhosis, he said yes. I then asked him if he would write to the Skipton fund to enable me to receive stage 2 funding. He kindly agreed.
46. Once I had sent the form and it was accepted I received £50,000 in October 2012. From October 2012 to the present day, I received monthly payments of £1,157, which has now gone up to £1,500. My reference number for the Skipton fund is 3683. At Christmas they also send a £500 winter fuel payment.
47. However, I did encounter some problems, I was having issues with the benefits system, I overcame this by ringing the NHS business service and was told that I did not have to disclose any information, as my payments from Skipton remained separate. I was told to contact a financial expert. The financial expert took nine months to sort out my benefits. The time delay was not his fault but the benefits system. I am very grateful for Mr Bateman's help with this.
48. As of March 2018 I now get state pension and pension credit, I receive a small pension from work and disability allowance from the NHS business compensation. I also eventually received the full back payments.
49. As previously mentioned, I would have preferred my money in a lump sum so that I can get on with my life. I am getting old now and would like the money given to me so that I can make the necessary arrangements. My liver could take a turn for the worse and I want to get things settled. I feel as though it is not settled at the moment. However, the money can never replace the life I have lost. The payment I receive cannot account for the trouble and hardship that I have been through. The infection with HCV has destroyed my life.

Section 8. Other Issues

50. The Haemophiliac society has been pressuring me to be represented by them. However, I have decided to not be represented. I receive countless emails from them asking me to join. I am constantly

pressured to donate money to them. I have heard that previously, they were not very interested in Haemophiliacs and that all they were interested in was what the government wanted them to be involved with. They toed the party line. Now I have heard they are representing the Haemophiliacs but for me it is too late.

51. I would like the inquiry to know that I am aware of possible criminality involved in giving infected products to Haemophiliacs and other patients. I think whoever has facilitated this, needs to be brought to justice, held accountable and prosecuted. Someone needs to take responsibility. If there has been criminality I want them brought to book because of how it has destroyed mine and so many other lives.
52. Unfortunately due to my illness and mobility issues I will not be able to attend any of the hearings to give my evidence. That said, I very much want my story to be heard.

Statement of Truth

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

Signed _____

GRO-C

Dated: 24th January 2019.