

Witness Name: Kirk Ellis
Statement No: WITN2331001
Exhibits: WITN2331002-WITN2331006
Dated: 19th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KIRK ELLIS

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Kirk Ellis will say as follows:-

1. Introduction

1. My name is Kirk Ellis. My date of birth is GRO-C 1981. My address is known to the Inquiry. I'm 38 years old and living with my fiancé and my two year old son. I'm currently struggling with my medical condition even though I've cleared the Hepatitis C virus after four different types of treatment. I still have anxiety over leaving my partner and son if I pass away.

2. How Infected

1. I was born with Haemophilia A and it was mild. However, there was confusion over this because my parents were told that it was severe at first. They were told by the doctors that I needed Factor VIII straight away. They diagnosed me with Haemophilia when I was 18 months old however there is no record of this. A lot of my records are missing but they all seem to be turning up now that the Infected Blood Inquiry has become involved.
2. I live in GRO-C so I'm under the Gwent Health Board when it comes to my medical treatment. Leading up to my diagnosis with Haemophilia, I was rushed into the Royal Gwent Hospital in Newport for bleeding and bruising that I had because of a fall which my parents were concerned about. The doctors in Newport ran tests on me but couldn't tell my parents what was wrong. My mother thought that I had Leukaemia as she knew someone in the village who had it. The doctors at the Royal Gwent Hospital told my parents that I was being transferred to the Heath Hospital in Cardiff where I was seen by GRO-D for something to do with my Haemoglobin. That's when my parents were told I had severe Haemophilia. As time went on my mother had to take me back and forth to the hospital.
3. From talking to other parents, my mother had questions as to why my condition wasn't as bad as other children who had severe Haemophilia- she knew something wasn't right. When GRO-D was away, another doctor made a comment that he didn't know why she had a problem as I was a mild Haemophiliac. My mother now thinks that that she was led to believe my condition was severe in order to get me on to the Factor VIII. For mild Haemophilia there were other, less invasive, types of treatment such as ice packs and blood Cryoprecipitate plasma treatment. My mother wasn't shown any test results when I was diagnosed with Haemophilia, she was just told.
4. I was told I had Hepatitis C when I was 15 years old. This was when I had a fall and I admitted to the doctor that I had been drinking. That's why they called both me and my parents in for a meeting where I was told that I should stop drinking because I had a Hepatitis C infection and that drinking would

make it worse. I can't help but wonder that if I hadn't started drinking, would they have told me?

5. My medical records claim that my mother was told I had Hepatitis C in February 1993 when I was 11. My mother said that she was not told and we found out when I was 15. I believe that the treatments I had over the year to treat my Hepatitis C made me suffer from depression and anxiety. The worry of having Hepatitis C which caused me to gain weight. After I was told I went off the rails. I put my parents through hell and blamed them for my situation. My mother blamed herself.

3. Other infections

1. I have just found out that I'm at risk of Creutzfeldt-Jakob disease (vCJD). I have received my records from The National Haemophilia Database. From the records I can see that I am at risk of vCJD as I was given the relevant batches that were taken from someone who had died from the disease. This is Exhibited before me at Exhibit WITN2331002.

4. Consent

1. Reading through my medical notes has shocked me. It says that as a child I appeared jaundiced and lethargic which is associated with liver problems. My mother doesn't remember them asking her if I could be tested for HIV, Hepatitis A, B or C. She wasn't aware of that. All they told her was that they were testing my Haemophilia levels.
2. Because my father was at work it was my mother who stayed with me when I went to the hospital. That's why it came as a shock to her when she found out from the doctors that I had contracted Hepatitis C at 15. One of my old blood samples had been kept for the purposes of being used for future testing and research which we were also not aware of.

5. Impact

1. Mentally, I didn't want to believe that I had Hepatitis C. I went off the rails. I was a 15 year old boy who was on the verge of becoming sexually active. I was making the effort to look after myself and look nice. As far as I was concerned I couldn't have children because I couldn't have unprotected sex. I believed that I would pass it on and didn't have a relationship for a long time. It was awful especially with the way I had been brought up. I spent a lot of time with my Nan and Bamps who were very family orientated and so I really wanted kids. My Grandfather said I could adopt but this wasn't what I wanted. I said to myself that if I couldn't have a family then I would have to find comfort in something else which ended up being drink and drugs. It wasn't until some years later when my friends, who also had Hepatitis C, had children that I realised it was possible.
2. I put my parents through hell with drinking, stealing and taking drugs. I completely stopped my education. I didn't see the point of GCSE's or A-Levels as I believed that the infection was going to kill me anyway. However, further down the line I got into carpentry at college. It took about a year for me to calm down and do something educational and learn a trade. I was always making things out the back garden at home. My Gran and Granddad told me that I needed to do something useful with my life. College was one of the things which helped me level out. My reading and writing wasn't great so I ended up failing the last part of the course as it was mostly writing. At the time I didn't know what I wanted to do with my life. I don't know how I managed to find a job in the end. I was very lucky.
3. Physically, I was drained; I fell into a cycle of alcohol and drug taking. This caused me to fall over a lot with my Haemophilia. People used to ask me why I drank so much. It got to the point where I would come in from work just to get changed and go back out to have a drink. I couldn't understand how I had gone from being a severe Haemophiliac to a mild. Because I've had the

Hepatitis C infection my Haemophilia has gotten worse. Not only are there the mental effects but it has also affected my body and its ability to control my Haemophilia.

4. My condition was really hard on my mother. It had a huge mental effect on her and she broke down a lot. She blamed herself for me going off the rails even though I told her not to. After watching the Panorama documentaries on those infected with contaminated blood she would tell me that she didn't realise that she was, in her words, "playing Russian Roulette" with my life every time she took me to the hospital for treatment. She told me that if she could go back in time she would have refused the treatment. This is something she still believes today. She believes she was lied to by the doctors. The doctors were adamant that I was a severe Haemophiliac and made out that having Factor VIII was a miracle drug so off course she jumped at it. She only began to think that something was wrong further down the years.
5. From the Panorama documentaries she heard the word PUPs which stood for Previously Untreated Patients. I used to get really aggressive watching programs about it; I couldn't help but feel angry. The statue of GRO-D is still there in the Heath Hospital and I just want to pull it down. It's weird to think that my mother used to call him "God" back then. Before I was diagnosed with Haemophilia my mother thought I had Leukaemia but GRO-D calmed her down by telling her I only had Haemophilia and that everything was going to be ok. But of course it wasn't as I was told I was a severe Haemophiliac when I wasn't and got infected with Hepatitis C as a result of being treatment that I did not need.
6. Luckily, there wasn't much of a stigma surrounding my infection. We didn't find out until I was 15. I told my family, friends and colleagues. I think the only time I felt stigma was when I was a child and I heard someone say "you can't let him do that/ touch that". We told everyone straight away why I had Hepatitis C. They were very understanding but I think that was because of the attitude we had to it. It was the way my parents brought me up and protected me. They

would confront those they heard talking behind my back. My Grandfather would say "Just tell people- be open".

7. I think that at the time there was a difference in the stigma towards HIV and Hepatitis C. There was a difference between the ways the media portrayed it. They made out that HIV was linked to sexual activity and hard drug taking. People with haemophilia who had HIV had to justify it. The attitude towards Hepatitis C wasn't quite as bad because it wasn't really known as much. At the time people thought that Hepatitis C wasn't as much of a death sentence as HIV as there were ways to cure it however, looking back I'd say it is a death sentence. My Grandad was very knowledgeable and told me that it was up to me to dispel any stigma people may have had of Hepatitis C by telling them that it couldn't be passed on unless there was large blood to blood contact. Gloves would have to be put on if I had a serious cut.

6. Treatment/Care Support

1. I've had four lots of treatment, two of which were Interferon. Three lots of the treatment didn't work at all but the last lot did, hence why I'm now clear of Hepatitis C. The side effects I had from the first lot of treatment weren't too bad although with the second lot of treatment which was Peginterferon and Ribavirin in 2009, I did get fatigue and depression. I would binge eat. When I was 21 I was still drinking and enjoyed going out with my mates and I told the doctor that. This put pressure on my joints though my Haemophilia. What they do is test how well you do on the treatment for 12 weeks and then, depending on how well you do, they carry it on. The doctors told me it wasn't working for me and eventually I agreed and they took me off it. Exhibited before me at Exhibit WITN2331003 is a piece of Data from the National Haemophilia Database.
2. My alainine aminotransferase (ATL's) had risen with the drink and drugs. Before I began my second course of treatment. I started seeing a counsellor through the Haemophilia Centre. Looking back I think it was a good idea to

see the psychologist as well as a doctor. At this point I didn't trust doctors, especially male ones. It was like there was a barrier there as it was like they didn't take me seriously. When I saw a female psychiatrist she said that the drugs would have better effects if I was living healthier.

3. The first 12 weeks on the new treatment of Peginterferon and Ribavirin I didn't drink. My ATL's had reduced by 0.5. The doctors assured me that because I had lived a healthy lifestyle for the past 12 weeks it had gone down instead of up. Despite this I got rashes around the injection points, I had suicidal thoughts, heart palpitations and tiredness. I put on two stone. They then put me on the anti depressant Citalopram which was initially a dosage of 10mg. They knew that I ate a lot when I was on the drugs. I went back to the doctors after six weeks where they increased my dosage of Citalopram to 40mg because I was gaining weight so fast. Because they increased my dosage I stopped gaining weight in the last few weeks of treatment. However, the treatment wasn't working anyway.
4. Over the next four weeks I put half a stone on. The doctors felt that there was no point in carrying on the treatment over the rest of the year. I had depression, I was snapping at everyone and everything. I was short-tempered with my mother; I smashed a cabinet with a hammer. I didn't want to go anywhere. I was off work a lot with depression. I always told them it was Haemophilia which is probably why they kept me so long.
5. Because I had stopped drinking before the treatment I turned to binge eating in the house. I felt that the drugs weren't working at all. Within a month I had lowered my hours in work. It was like I either went into work or took the drugs. My blood count had dropped from four million to 1,000 counts during the third lot of treatment. I was tired and having suicidal thoughts. At the time my partner was pregnant and I was more hormonal than her! I didn't think that the treatment wasn't working as well as it had on others.
6. At first there was enough funding at the Haemophilia Centre so that I could be seen by a liver specialist. Unfortunately, that funding was taken away and we

were chucked in with all the drug addicts and alcoholics at the Blood Borne Viruses Clinic. This is Exhibited before me at Exhibit WITN2331004 in an email from Haemophilia Wales (on behalf of myself) to the Chief Executive of the Caxton Foundation and McFarlane Trust Jan Barlow. It says:

"In Wales we have a situation where we have not had a Hepatologist since 2007 when Doctor Aspinall left his post and consequently Haemophiliacs with Hepatitis C (and all other patients) have not been monitored by a liver specialist."

7. I felt like we were brushed under the carpet and that they didn't want us at the Haemophilia Centre. This was of no fault of my own or my parents. We were palmed off basically. We told by the doctors to "Go sit with the rest of them (drug addicts)". I felt dirty although I was frequently told by a few doctors that it wasn't my fault.
8. When the funding was taken away and we were forced in with the drug addicts, the doctors would look down on you. They would ask questions about how much alcohol I'd been drinking. I was confused as to what that had to do with the National Health Service giving us infected blood. It's like the doctors were belittling us.
9. I found out a few years ago that I have cirrhosis of the liver. It was a complete shock to be told that I had two readings that had shown cirrhosis in the past. I believe I should have been told in the doctors' meeting in May 2015 after I had a Fibroscan showing a score of 14.4 when a score of 12.5 and above would indicate liver cirrhosis. I was only told in October 2016 when I asked the doctors if I could postpone my treatment to the Summer when I would feel less down. I was told my liver had gone from being non-cirrhotic to cirrhotic. Exhibited before me at Exhibit WITN2331005 is a letter from my UHW Consultant at the time, Doctor Srivastava to Doctor Rajan at the Aber Medical Centre in Abertridwr, Caerphilly.

10. At the time it was hard because I had a child on the way. If I had known earlier me and my partner wouldn't have had a child. My liver is damaged to the stage that it may not repair itself. I had gone from having the Hepatitis C infection to having Hepatitis C and cirrhosis of the liver in a year and a half. I have this fear of leaving my son without a father.
11. I only found out that the new treatments had become available through a friend who was doing the drug trials for them. I was told that because I came under the Gwent Health Board I had to wait for funding in order to get on the treatment. It was as if the Cardiff Health Board didn't want to pick up the £50,000 bill for my treatment even though it was the Heath Hospital that had given me the infection.
12. Because I had cirrhosis I could apply for Stage Two of the Skipton Fund. However, I believe the doctors didn't tell me about my cirrhosis in May 2015 because I had early stage cirrhosis and wanted to place me on the new treatment and hope my liver repaired itself. I also would never have known I had it. In this case, I wouldn't have been able to claim Stage Two Skipton Payments. I also wouldn't have known that in the year and a half they made me wait for the treatment my liver had gotten worse. The doctor eventually signed me off work so that I could start the treatment.
13. Because of the cirrhosis I have sleepless nights as I'm always anxious. Any pains I have in my stomach I think it's my liver. My partner tells me that it's just indigestion but I think it's my liver. It's a waiting game all the time. I can't do anything until they tell me that my liver has repaired itself.

7. Financial Assistance

1. When the Skipton Fund first started, I think it was in 2004, I had an initial payment of £20,000. As soon as I received it my mother told me that my sister was having the £5,000 I had stolen from her, which I paid. I also paid my grandfather £900 he had used to pay bailiffs off for me. Within three months

the £15,000 was gone. I had spent it on drinking, drugs and gambling. I felt that I had nothing to live for. It was only when my sister had a baby that I calmed down.

2. I wasn't told when the Caxton Fund was set up and only found out about it when they were shutting down. I only had the one winter fuel payment. It's frustrating because in the time I was off work because of my Hepatitis C I could have been applying to Caxton. With that extra money I could have helped my mother out with all the expenses of looking after me. I was having night sweats and my mother had to frequently change the mattress. The money from Caxton could have paid for that. When I asked why I hadn't been told about them they claimed that they didn't know where I lived even though I've always lived in my mother's house.
3. On the financial support side of it, there's been a huge difference between the devolved nations. If I was infected in England I'd have been £3,500 a year better off. If I'd been infected in Scotland I'd have been £8,500 better off a year. The way I see it, we were all infected by the British National Health Service so the support should come from the Treasury not the devolved nations. It's discriminatory. It's like my life isn't worth as much as someone else's. They need to make to level payment across the board.
4. Once I was informed that I had cirrhosis of the liver and therefore entitled to Stage Two money, the money went in at the beginning of October once the doctor had signed the forms. This was £50,000 which went straight into Premium Bonds for my partner and my baby just in case the treatment didn't work. I waited for the regular payments in December before I started the treatment. I just wanted to know that I was going to be getting a regular payment. I told them that as soon as I got the money it was going into because I have cirrhosis I want my partner and baby to be financially secure even though I'd rather have my health back and no money.
5. Support schemes wouldn't backdate the Stage Two Skipton payments, saying that they could only pay me from the day I had applied. It's frustrating as

there's no way I could have applied until I was told about my cirrhosis and that was only one and a half years ago. This is Exhibited before me at Exhibit WITN2331006 in a response email from the Chief Executive of the Caxton Foundation and McFarlane Trust Jan Barlow. At the moment I'm in the very early stages of cirrhosis so hopefully it repairs itself. I've got to wait 12-18 months post treatment and then I'll go in for another scan to see if my liver will repair itself.

8. Other Issues

1. What I want from this Inquiry is the truth and justice. Someone has to be held accountable but it seems that this won't happen unless they can pinpoint one person. No-one has admitted liability. I used to say that the person responsible should go to prison but now all I want is accountability. There's been no proper apology or anything in the post acknowledging what happened. It's been made to look like an accident but a lot of people knew, a lot of the doctors knew and chose not to tell people. Letters from GRO-D GRO-D prove this.
2. American drug companies knew that the batches would cause problems but that Britain would accept it anyway because of cost cutting. My mother feels like her legal right to make decisions concerning my treatment was taken away from her. It hurt me a lot when she made the comment that she felt she hadn't looked after me tidy. I told her that she had but then again you can't help if you haven't been given the correct information.
3. For me, it wasn't just the cover-up of being infected with Hepatitis C but also not being told about the cirrhosis until I asked for my treatment to be postponed. Why wasn't I told in the first year and a half? I remember seeing the story about Colin Smith on the TV. He had Haemophilia and was given infected blood about the same time as me and in the same hospital. He died aged seven of Hepatitis C and HIV. I recall my mother telling me that it could have been me that received the HIV batch but thankfully I was given the

Hepatitis C batch; and that's how close it was. They poisoned me as far as I'm concerned. But I'm alive when a lot people died which I'm grateful for, especially now I have my son.

Statement of Truth

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

Signed: GRO-C

Dated 19/2/2019