

Witness Name: Mr Darren Rawson

Statement No.: WITN1963001

Exhibits: 0

Dated: 14 February 2019

**WITNESS STATEMENT OF MR DARREN RAWSON
INFECTED BLOOD INQUIRY**

Section 1: Introduction

1. My name is Darren Rawson. My date of birth and address are known to the Inquiry.

2. I live at home with my wife and my two young children who are six and five years old. My six year old GRO-C
GRO-C He demands a significant amount of extra care from my wife and me.

3. My mum and dad live close by.

Section 2: How Infected

4. According to what my mum has told me, it was late summer or early autumn in 1988 and I was only five years old. My parents, my brother and I were moving

home. I had just had my tonsils out; the operation took place about two days previous, so I was still recovering. Out of the blue, I started to froth at the mouth and seconds later, to haemorrhage from the mouth. I was screaming and crying. I remember that I was in my mum's arms and standing at the top of the street waiting on the ambulance to arrive. I was rushed to Hull Royal Infirmary; the same hospital where I had my tonsils out. When we arrived I was taken to a ward while the doctors tried to establish what was wrong. Mum informed the doctors that I had my tonsils out. I was taken for an x-ray and my mum was told that during the tonsillectomy, the surgeons had left a tag on my adenoids and this was causing the bleeding. I was placed on an intravenous drip and around one to two hours later taken back to theatre to have the tag removed. My mum thought I was dying. It was during the operation to have the tag removed that I was given a blood transfusion; my mum tells me that I lost two pints of blood that day and was given two pints to replace what I had lost. It was not until 2009 or 2010 when there was an article that appeared in the local paper, that my family and I started to piece things together properly. The article discussed blood transfusions and the fact that you could become infected with hepatitis C. My mum read this and contacted me to say that I had a blood transfusion when I was five. Up until that point I did not know why I was so sick or how I had contracted the virus. Following a request for records in 2015, I received a letter from Hull and East Yorkshire Hospitals NHS Trust dated 24 February 2015 which states *"according to our records you were given blood in 1988 and this was done in the belief that the blood from the transfusion service was safe and heat treated. We have formally requested if the Blood Transfusion Service could trace the blood given to you but they do not keep records this far back. As our investigations stand we acknowledge that it may have been the blood transfusion that caused your Hepatitis C infection and if this is the case we sincerely apologise. However, we are unable to confirm this"*.

5. I was not infected as a result of a relationship with another person. There is no other way that I could have been infected other than through the blood

transfusion.

6. My mum has told me that the doctors spoke to her before the operation to ask for her permission for me to have the operation to remove the tag and a blood transfusion. They said that I needed one as I had lost so much blood. My mum was not told about any risk that might have been associated with receiving the blood.
7. I have been infected with hepatitis C only.
8. I found out that I had been infected with hepatitis C in 2004. I had started to suffer from severe nose bleeds which came on all of sudden one day. I was having them quite frequently, perhaps one every two to three days. One particular day I was walking home from the town centre in Hull; I had just been to sign on and I was going to an interview for a job on my route home. I was still living with my parents at the time. I was almost home when my nose exploded and I was covered in blood; it was like I had an open wound that would not stop bleeding. It looked like someone had attacked me. The blood would not stop. I had to take my top off and wrap it around my face until I got home. My nose continued to bleed for another 20 minutes or so. I did not think anything of this at the time until two days later when it happened again, although the second one was not as severe as the first. Three days later it happened again and this time it was as severe as the first. It happened around four times in total before I eventually went to see my GP. The GP requested some blood tests. I waited for around seven days for the results to come back. The GP called me in to see him and gave me the results of the tests. He told me that he had looked at my records and from the blood test results I had contracted hepatitis C. In all, from when the nose bleeds started I was told within two weeks. He did not say why or how he had reached that conclusion but he did say that he was referring me to a specialist.
9. When I was told I had hepatitis C I asked my GP what it was and how I could have contracted it. He did not answer my questions; he totally ignored me and

just restated what he had just said; that he was referring me to the hepatitis C specialist at Hull Royal Infirmary.

10. At the point in time that my GP informed me I was infected, I was not given any information to help me understand and manage the infection. When I finally got to see the hepatitis C specialist; approximately six to eight months later, she asked me questions about how I might have contracted the infection. I was asked if I was a drug user; this made me angry. I responded by saying "you are joking aren't you". I was asked if I had injected myself. I showed the specialist my arms and I asked her if it looked like I was or had been injecting myself. She asked if I had a sexual partner. I answered no. At the time I was single and had not had a sexual partner before. She told me that she was going to do some more tests on me. I think it was to see how bad the virus was. I asked her how I could have caught it and what impact it was going to have on my life. I felt dirty; from the first day I found out from my GP. She told me I would be fine. I did not know what to think. I was confused. If I was fine then why was she sending me for more tests? I was given no information at all. I did not understand and was not able to plan to manage the infection. I had to research it all myself. I used the internet when I could access it to do this.
11. I think that my mum should have been informed about the risk of infection when I was given the blood in 1988, then, we could have been alert to the fact that my side effects might have related to that. I certainly feel as though I should have been given information when I was told by my GP in 2004 and then when I saw the consultant after. Instead I was totally left in the dark.
12. It was appalling the way I was told, both by the GP and the consultant. It was appalling what I was not told. It was appalling how I was put under the spotlight to answer questions about how I had come to be infected when this information should have been given to me. It was appalling that none of my questions were answered.
13. I was given no information about the risks of others being infected. I had to do

my own research and inform myself. I found out I could not use someone else's razor or toothbrush; I found out that I should always use protection during sexual intercourse. I realised that I had to avoid blood to blood contact.

Section 3: Other infections

14. I believe I have been infected with hepatitis C only;

Section 4: Consent

15. I believe that I was:

16. Treated without my full knowledge,

17. Without my full consent; and

18. Without being given adequate or full information. My mum was never told about the risk of infection to me or any risk associated with receiving blood. If my mum had been told there was a risk, then she might have decided that I should not have the transfusion and she might have sought other means of treatment for me to avoid any risk.

19. Looking back on this now, I believe I was treated and tested for the purposes of research. I think I was used as a guinea pig, this because the blood was not screened at the time.

Section 5: Impact

20. The impact of the infection of my life has been massive.

21. I think the mental impact of this has been the hardest thing for me to deal with.

22. When I first found out I had the hepatitis C I immediately felt really dirty, I immediately connected it to HIV. I felt even dirtier after I had researched it. I had heard about hepatitis A but not hepatitis C. I connected it to HIV and to drug users and I thought that what I had was something similar; especially because of the questions I was being asked. I hated knowing that there was something in my body that should not be there. I remember I took a bath for nearly four hours one day to try to cleanse myself of it. I knew that it was pointless. After the doctor had told me and I was able to do a little bit of research, the best way to describe how I felt was that I nearly exploded; it was completely overwhelming. I just did not know what to do. It was like my life had immediately taken a turn for the worst. I remember thinking that I could not have a relationship in case I passed the virus on. I was too scared to tell people I had it. I kept it to myself for a long time. Depression started to set in. The fact that I have been infected was constantly on mind; I was thinking all sorts, all of time. I asked myself why me, I could not understand how this had happened to me. I took to drinking for a while. I drank to try to forget what I was dealing with and to have a couple of hours in the day when I did not have to worry about it. At this point I still did not know how I had been infected; I knew nothing about the ways in which the virus could be transmitted. Through some further research I found out that you could be infected through receiving a blood transfusion but at this stage I did not know that I had one. After about three or four months of the binging, I began to ask myself why I was drinking and I decided to speak to my parents about what had happened. When I informed them about what happened, I stopped drinking completely. At the time, none of us had the answers. I visited my GP who put me on a course of anti-depressants for about one month. He told me to see how they might work out. He was reluctant to prescribe any more than that because he was unsure of the impact on my liver. I continued to struggle and had at this point developed anxiety which I still have today. I tried to get along with my life the best I could. My family were very supportive. In 2010, I read an article that appeared in the local paper which discussed hepatitis C. My mum had read the

article too, she was aware that I had a blood transfusion and raised the article and the fact I had a blood transfusion with me. Very slowly things started to make sense. I was reluctant to accept that my infection could be down to the blood transfusion. I went back to my specialist and I asked her if I could have caught the hepatitis C from a blood transfusion. I told her about the article and explained that I had a transfusion in 1988 and that it was the only transfusion that I had ever had. She ignored me. She changed the subject. I asked her again and I asked her why she had skipped over the question I had just asked her. She turned around and said that she could not answer it. I told her that this was no good. I asked her what quality of life I was going to have. She told me again that I was going to be fine. I did not believe her. I had done some research and I had my worries. I had seen the article which showed that people had been let down by the system. I knew there was more to it. My head just blew. I was totally frustrated; I was not getting any answers despite my pleas for years, for answers and for help. This made me feel so angry like I did not matter, like I was just another number in a system that did not care. I went out and started drinking again. I could not cope. I felt completely alone and completely let down. Not supported at all by medical profession. At this point I was living in my own place and on my own. One night when I got drunk I decided I was going to end my life. I took steps to hang myself in my kitchen. I woke up the next day in the hospital and I did not remember what I had tried to do. I spoke to a crisis team, they told me that my neighbour had heard a loud bang and had come up the stairs to my flat to find me in my kitchen. She rang for an ambulance. When I went back home, I saw the step ladder on the floor of the kitchen and a noose; a tie, tied around the light fitting. My mum came to the flat and asked me what I had done. She saw what I was seeing. My parents took me to their house for a couple of days. The depression has continued. I have tried to cope with it by myself; feeling proud to degree that I did not need to go on more drugs. I still get suicidal thoughts but I am trying; despite a failing health service which repeatedly fails to support me and my needs, to work through it for my family and my partner. There are no words that could possibly describe the impact of this. Even now, I still ask myself

every single day why have they lied. It was not until last year that my doctor put me back on tablets for depression; I had started to feel really down again and went to drive my car off a cliff. Luckily I came to my senses and I sought help. Over the years, as I have learned more and more about this scandal, I have become angrier about it. I understand better now the seriousness of it. I was brought up to respect the National Health Service; our public health service. I cannot describe how angry I feel to know that it was this public health service that infected me with this disease. I am angry that the system did not protect me when it should have done. I have trusted that the system including the medical professional would have to take care of me for years. My mum did too. That trust has gone and I have been left feeling totally vulnerable as a person and completely let down. I feel particularly vulnerable because I now have to seek help from the system that has hurt me so badly. I simply cannot trust it now.

23. The physical impact of this has been huge too. The first physical symptom that I experienced was extreme tiredness, deep fatigue. My sleep pattern is totally unpredictable and I am tired most of the time. I suffer from pains in my joints; particularly in my hands and fingers, and they lock on me. My feet also bother me. The pain can stop me going about my day to day business. I suffer with a lot of cramp, this happens every day in my legs. I suffer from itchiness, all over my body, day and night. It does my head in. It gets really bad and sometimes I bleed because I have scratched too much. Nothing helps. I have problems with pain from the liver itself. I get sharp stabbing pains. My immune system is weakened so I get colds and flus all the time and am at threat of pneumonia. I have had pneumonia six times in the last two years. I also have problems with my breathing. I am on a purple inhaler; I am also being tested for Chronic Obstructive Pulmonary Disease. I am unsure as to whether the immune system problems and the breathing difficulties are as a result of the hepatitis C or the treatment for it, but, I do believe that both symptoms have worsened since the treatment. I also suffer from brain fog. This is different to tiredness. I totally forget things that I am talking about mid sentence. I forget where I place

- things. I suffer with acid reflux too. I have had problems in my stomach but when I have been checked out nothing has been found.
24. I was diagnosed with hemochromatosis in around 2016; I understand that this has resulted from the infection. I do not know whether I have any other condition or medical complications as a result.
 25. I was given harvoni for the hepatitis C in 2015. I took it for two months and it cleared the virus.
 26. I was diagnosed in 2004 and not treated until 2015. Can someone please find out why? I was visiting the specialist approximately every year. She kept saying, I'll see you next year. Waiting this long panicked me. I was very scared that my condition was worsening. In 2015 I had a biopsy of the liver. This was the first time I had a biopsy. The results of the biopsy dated 30 January 2015 state that the "increased in ARFI reading indicates an increase in liver stiffness and associated fibrosis". In July 2015 my hepatitis C was described as at least Stage 3 hepatitis C and my viral load in August 2015 was 474,000. In the paperwork to support my application for financial assistance, my consultant has described my condition as "at least Stage 3 fibrosis with some features of Stage 4, so he remains at risk of significant complications including increased risk of hepatocellular carcinoma. It is likely he has some chronic fatigue related to his underlying hep c liver disease. The plan is for continued monitoring and surveillance for HCC and complications". Despite all of this I have not seen a specialist since April 2018 and this worries me greatly.
 27. I think I should have been treated earlier than I was; at the latest, when they found out I had the hepatitis C. I also think I should be followed up now every six months particularly given what my specialist has written above. I cannot understand why I have not been called for follow up appointments.
 28. The harvoni treatment was not too bad. I felt a little more tired than usual on it and I think that my immune system and breathing difficulties have worsened as

a result of it. I also noticed that my motivation suffered when I came off it.

29. I have had to tell my dentist that I have hepatitis C but the treatment was fairly straight forward. I do not think that my infected status has affected treatment, medical or dental care for any other conditions.

30. Initially when I found I was infected I decided I was never going to have a close relationship with anyone and I closed myself off from my family and friends. When I met my now wife, I told her very early on that I was infected with hepatitis C. The thought of telling her caused me a lot of anxiety, and I had to think long and hard about it. I had to be sure that we had the potential for a future and I had to be sure that I protected her. GRO-C
GRO-C I used to worry all the time that my wife and my children could become infected.

31. Up until 2016; before I had cleared the virus and before infected and affected people really started talking out about this scandal, I had told no one about it other than my parents and my wife. This was purely down to the fact that I was constantly worried what people would think of me and what impact it would have on my life if they found out. I worried about being trolled on Facebook; being bullied, harassed and attacked. I kept the information very close to me. I have started to tell people now since I cleared the virus; I was on the local news in around 2017 talking about it as I wanted to try and help people who might have had the same experience as me.

32. I was infected when I was five years old. I am not able to say what life I would have lived if I had not been infected. I am not able to compare this with anything. I believe therefore that the impact of this has been very broad and has reached into every single aspect of my life.

33. I went to school but I did not sit my exams. I struggled in school with dyslexia. I remember being tired from time to time and falling asleep on the chair at school.

34. I used to work as a Red Coat at Butlin's. I worked there for three months in 2001 or 2002. My work came to an end because I was too tired. The hours were long and I could not cope with them. It was too stressful for me to cope with. I also worked at a caravan company for one month, which is what the contract was for. Other than this I have never worked.
35. I cannot get a mortgage. My credit scoring is terrible and a regular income is required to boost your score. It is impossible for me to be able to afford anything. I struggle even to get a TV because I have no ability to get credit. I live on the money I get from the England Infected Blood Support Scheme (EIBSS) and Employment Support Allowance (ESA) payments. I get Child Tax and Child Benefits. My life is controlled by the benefits I receive which are not enough to help me to live my life even in a very basic way. I feel like I have been downgraded in life. I am confined to a life on benefits which is something I do not want.
36. The impact of this on my partner and my children is huge. The physical and mental impact of this on me has made it impossible; in some ways, for me to be the partner and father I would like to be to them. For example, I am not able to work in order to provide a better lifestyle for them. The fact I have been infected has caused my parents and grandparents to worry a lot. My mum GRO-C and me being so ill has had an impact on that. My mum has said that if she knew at the time what they were putting into me, she would not have consented to the transfusion and would have sought advice about other options.

Section 6: Treatment/Care/Support

37. Yes, I have faced many difficulties and obstacles in obtaining treatment and care and support and I have done throughout the entire period of this virus coming into my life. I was infected in 1988. I was informed in 2004. I was treated in 2016. Why the delay? I do not understand it. I have never received

any care or support through this and I think this is why I have struggled so much with the depression. The worst of it has been the lack of information; the lack of the medical profession managing my condition for me and with me. I have no clarity on what is happening, at all and despite repeated attempted to find out what is happening with my life. I feel like I'm constantly being fobbed off. Even when I have asked questions because I have desperately needed to know answers, I have been ignored. My GP practice is dreadful. I constantly struggle to get appointments and support. I asked for a letter to support my EIBSS application and was still chasing it nine months later. I was trying to get an appointment to see my GP so he could repeat-prescribe my anti-depressants for around three months. This is serious. I have attempted suicide. I had run out of them completely in early December and was very worried about how I might respond to not having them. I have just been to see my GP for this have been told that he does not want to prescribe me them again until I come off the anti-biotics that I am taking for my chest infection. He is worried about the effect the anti-depressants will have on my liver. I don't understand this because I need them; I am worried about my mental health. It is hard enough for me to try and live with this virus but to have to fight to get support to be able to survive through it is too much.

38. Counselling and psychological support has not been offered to me in consequence of being infected. When I have gone to my GP and told him I am depressed I have been given a card for the Let's Talk service with a number on it to call. I have never been offered support; I have had to request it. The Let's Talk service has not worked and I have told the GP this. It was totally inadequate for my needs. They kept repeating themselves; not remembering what I had told them. There was no plan put in place to help me. Last year I had to do something because I knew I was heading into a very dark place. I went to my GP again. I told him I was feeling really depressed and suicidal, I told him that Let's Talk was not helping. I was put on some medication. He gave me the Let's Talk card again even though I told him it wholly inadequate. He told me that this was all he could offer. I went back to him again and was

put on a higher dose of depression tablets. I have not had these tablets since November/ December last year. Between the GP and the Let's Talk service which I have tried again, I cannot get help because of waiting lists. I referred myself to a hypnotist last year which seems to have worked ok. I would like to go back but I was only able to go because I got the funding for it from EIBSS and I am unsure as to whether they will support me with this again. The initial funding took about three months to obtain and eight lessons cost a total of £480. I think people's needs vary and for me, I seem to respond better to action rather than just talking.

Section 7: Financial Assistance

39. I have received financial assistance from Skipton, Caxton and EIBSS Funds.
40. The first time I found out that there was financial assistance was in around 2012. I think that I found out through searching on the internet. I think I went onto the Hepatitis C Trust website and I found a link on there. I knew nothing about the Caxton Foundation until around 2014, when a fellow infected person told me.

41. I have received the following:

£20,000.00 from Skipton Fund in 2012;

£1,001.72 from Caxton Foundation from 24 September 2015 as a back payment;

£291.67 on 1 October 2015, and every month thereafter up to and including 1 October 2017;

£257.50 from Skipton Fund on 20 June 2017;

£252.50 from Skipton Fund on 20 July 2017 and every month thereafter up to and including 1 October 2017;

£291.67 from EIBSS on 1 November 2017 and every month thereafter up to and including 29 June 2018;

£252.50 from EIBSS on 1 November 2017 and every month thereafter up to and including 20 March 2017;

£796.67 from EIBSS on 1 December 2017;

£333.33* from EIBSS from 20 April 2018 and every month thereafter to date (note: *4p more on 20 April 2018);

£2,316.84 respite from EIBSS, on 25 May 2018;

£2,158.32 back payment from EIBSS, 31 July 2018;

£945.00 from EIBSS on 31 August 2018;

I repaid £400.00 to EIBSS on 5 September 2018, they said they overpaid me;

£420.00 from EIBSS on 01 October 2018 (one off discretionary payment for counselling);

£595.00 from EIBSS on 01 October 2018 and 01 November 2018;

£1,114.00 from EIBSS on 30 November 2018 (monthly payment and winter fuel allowance);

£595.00 from EIBSS on 01 December 2018 and every month thereafter up to date.

42. For Skipton the application required my specialist to fill out the form. It was sent directly from my specialist. I did not see it. I just handed it in. I have since been told that I should have received a copy to check. For Caxton the process was the same. I applied for the Skipton Special Category Mechanism (SCM) in around November 2017; I waited for three months for it to be returned by my GP to be told it had been lost. I sent another one which was completed by the GP and returned to me with a note which stated that it needed to be sent to my specialist. I sent it to my specialist which took another two months. At this point I was close to the deadline for the application submission. I spoke to EIBSS as I was worried I would miss the deadline. They said they would allow me some flexibility. I eventually sent the form in April 2018, almost six months later! They rejected the application in May 2018 and I received a letter in February 2019 setting out the reasons why *"application can only be authorised where there is evidence that on the balance of probabilities the hepatitis C infection and/ or its treatment is having a substantial and long term adverse impact on the applicants ability to carry out daily activities. The supporting medical information submitted in your application did not provide significant evidence that this is the case. The medical practitioner who helped complete your form and EIBSS medical assessors were unable to conclude that it is probable that your conditions are attributable to the hepatitis c infection and/ or the treatment"* and they sent me an application form to make a Stage Two application. To me this meant they wanted me to make a Stage Two application and I understood that I did not need to make another SCM application as they could use this from previous. I had to go through the process of sending the Stage Two application in to my specialist which took two to three months to complete. Once I received it back I sent it into EIBSS. They looked through it and rejected it again by saying there was not enough evidence. This was totally confusing to me; they asked me to make a Stage Two application when they knew I had made an SCM application and advised me I did not need to make another one. When I asked them why, they could not answer me. I appealed the decision in the summer last year. This was not

successful. The same reasons were offered, this is despite my specialist including information during the first application for the Stage Two that I had Stage Three hepatitis C with some evidence of Stage Four as indicated above. I am told that I cannot make another application until a period of six months has elapsed. It has turned out that my specialist did not include information about my mental health and so now I am left in limbo until I can make the application again and I fear that the same thing is going to happen. In fact when I have asked my specialist for assistance, she has refused. I think she is fed up with the paperwork. How do I overcome this problem?

43. I have indicated the problems in the system above but they include; levels of bureaucracy which are unnecessary and which cause significant delay. Systems that appear to be inconsistent in their approach. Unnecessary pre-conditions being placed regarding reapplications or appeals. I find the process totally and utterly stressful. I feel out of control with it because I am reliant on others filling out the paper work for me and they do not complete it properly; for example, in the previous applications, the information about my depression and mental health issues is not indicated on the application when this is a massive issue I have to deal with.
44. I am not aware of there being conditions imposed on the making of an application or the grant of financial assistance.
45. I obviously did not know that I had hepatitis C for very many years. Had I known this information I expect I would have been able to claim support because of the various ailments I had including in particular my mental health issues. This would have been a massive support me and my family and might have helped to avoid the situation that I found myself in. It might have avoided an enormous of stress and pressure on me in my life. I do not know why I have to get the consultant's or doctor's to fill out the paperwork, this process adds significant delay.

Section 8: Other Issues

46. At the moment I am awaiting receipt of my medical records and I would like the opportunity to submit a supplementary statement should evidence become available through that process that would be of assistance to the Inquiry.
47. I would like the Inquiry to find out the truth of what went on. I would like answers to my various questions. I would like to know why I received the blood that I received and whether it was really necessary for me to have it. I would like to find out why the citizens of this country were not informed about what was going on and about the risks to look out for. I want those that are responsible for this to hold their hands up, acknowledge that it happened and take responsibility for it. I want proper compensation for this, for security for myself and my family, for proper access to medical care and support that is accessible to me without a fight.

Signed: _____

GRO-C

Full Name: DARRON Rawson

Date: 14/02/19

Statement of Truth

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

Signed GRO-B

Full Name: DARREN Rawson.

Date: 14/02/19.