

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAIN ROBERT SQUIRES

I, Cain Robert Squires, will say as follows:-

Section 1. Introduction

1. My name is Cain Robert Squires of [GRO-C] Nottingham, [GRO-C] My date of birth is [GRO-C] 1975.
2. This statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

3. I have Haemophilia B. When I was younger the severity of this was classed as moderate but now it is mild.
4. I was treated at Queens Medical Centre (QMC) in Nottingham and Kings Mill Hospital in Sutton-In-Ashfield. My consultant at QMC was Dr Dolan.
5. I received Factor IX on a regular basis as and when required and have done so since I was a very young boy. I recall that on one occasion I was at Kings Mill Hospital and they did not have any Factor IX and I was therefore given an alternative treatment, via a drip. I am not sure what this treatment was.

6. I was infected with Hepatitis C as a result of receiving contaminated blood products. **Exhibit WITN1538002** is a letter dated 29th December 1992 from Dr Dolan at QMC to Dr Siddiqui which confirms that I had Hepatitis C which was almost certainly due to exposure to non-heat treated Factor IX concentrate. This letter also confirms that I showed evidence of chronic viraemia in that I was PCR positive.
7. I was not given any advice regarding the risks of receiving Factor IX. I am also of the view that my mother was given no advice in this regard when I was a minor. At that time we trusted the doctors implicitly and we only attended hospital if it was serious and therefore we would be unlikely to question any of their decisions.
8. I remember the day on which I was told that I had been infected with Hepatitis C which was in or around the early to mid 1990s. I attended a routine clinic appointment at the QMC and Dr Dolan told me that he had tested me for Hepatitis C and that I had tested positive for it. From that point on, everything was a blur. Dr Dolan continued to talk but I did not process anything he said because I thought that I was going to die. I was in complete shock. The only thing I took away from that meeting, apart from my bombshell diagnosis, was that I needed to stop drinking alcohol and apparently if I drank 30 units of alcohol each week I would definitely die.
9. I think that he also told me at this meeting, or at some point afterwards, that I could pass it on via sexual contact and that I had to be careful with blood spillages. I seem to recall that my brain managed to store this information which I believe was imparted to me by Dr Dolan at some stage.
10. I am very disappointed by the way in which Dr Dolan broke the news of my infection to me. He just launched straight in and I had absolutely no idea as to what he was going to tell me. I was certainly not expecting the news I got on that fateful day.

Section 3. Other Infections

11. **Exhibit WITN1538003** is a letter dated 20th September 2004 from Dr Dolan at QMC to my GP which confirms that I was put at risk of vCJD.

Section 4. Consent

12. Following the news of my Hepatitis C infection, I was then told by Dr Dolan that I had also been tested for HIV and that this was thankfully negative. Up to this point I had no idea that I was being tested for anything. It was all conducted without my knowledge and therefore without my consent. **Exhibit WITN1538002** confirms that I had been tested for Hepatitis B and HIV. I had no knowledge that these tests were being carried.
13. It came as a huge shock that I had been tested, probably on a regular basis, for viruses and that I had no idea about this.
14. Blood was routinely taken from me and no one ever explained why they were taking it.

Section 5. Impact

15. Prior to undergoing the Interferon and Ribavirin treatment in an attempt to cure my Hepatitis C, I would say that my health was fairly good. The only complaints I really had were extreme fatigue, poor memory and concentration.
16. Obviously, I was affected mentally by virtue of the very existence of my diagnosis. I was also very upset about how it could be transmitted to others and that I could not discuss what I was suffering from openly with others, for fear of the stigma.
17. I do recall a particular incident at work which reinforced the need for secrecy in relation to the virus. I worked for the civil service at the time and one of the female employees had been to see a client who had Hepatitis C and had returned to the office holding a form which the client had filled in. The form had blood on it and the female employee was trying not to touch the part of the form with the blood on and she was making comments which suggested that she thought that she could become infected with Hepatitis C just by touching this dried blood. It really hit home with me and I knew that I must not disclose my status to anyone, unless I was very sure that I could trust them implicitly.
18. It is very upsetting and stressful having to live with Hepatitis C on a day-to-day basis. I can't share it with anyone so people don't really know the "*real me*". It causes no end of strain in relation to sexual relationships because you have to be upfront with partners and

this causes problems in itself if you are in the early stages of a relationship and you don't really know the other person very well yet.

19. I did actually tell some close friends as time has gone on and I have become older. I have started to have more confidence in who I think I can trust and I think that I have made good judgements in this regard. I have, however, never disclosed my status to work colleagues.

20. I found it upsetting and frustrating being turned down for things because of my Hepatitis C and a good example of this is in relation to any insurance policies which I have tried to secure; all unsuccessfully unfortunately.

21. Hepatitis C has had a much more negative impact on my life post the Interferon and Ribavirin treatment. Prior to the treatment if I was feeling very lethargic I would need a day to recover but after the treatment, I can honestly say that I am completely drained and it takes me so long to recover.

22. I underwent my first treatment in relation to the Hepatitis C on 18th July 2002. **Exhibit WITN1538004** is a letter dated 18th July 2002 from Maggie Nicholls, Specialist Hepatitis Nurse to Dr AEM Lucassen which states "*Cain was seen in clinic today and was commenced on Peg/Interferon 180mcgs subcutaneously once weekly and Ribavirin 400 mg b.d as part of our expanded access programme*". I was completely absent for work for about 6 months because the side effects were truly horrific. I was stuck in the house all day, exhausted, nauseous and very depressed. I ended up taking anti-depressants and I have not recovered since.

23. During the first course of treatment, they told me about two thirds of the way through it that it was not working. Initially the medical professionals had been confident that it was working but soon after that they realised that it was not going to be successful.

24. **Exhibit WITN1538005** is a letter dated 3rd July 2008 from Dr Ryder, Consultant Physician/Hepatologist to Dr Dolan which confirms that I have Chronic Hepatitis C and that "*there are a number of new agents in trials for Hepatitis C at the moment which have the potential to significantly increase cure rates. These are still in clinical trial at the moment. I would anticipate within the next year or so we will have some fairly definitive information about the one which is furthest down the line in development, VX950. Preliminary evidence would suggest that there is something around a 20% improvement in sustained virological*

response using triple therapy with Interferon, Ribavirin and one of these agents. I have given Cain a 12 months review appointment for the clinic just so we have him in touch when these agents make it through their clinical trials".

25. I then commenced a second course of treatment in order to combat my virus at the end of 2014. This was a trial and it comprised of Ribavirin. I stayed on this treatment for circa 4 months and I recall that I was still on the treatment when I turned 40 in the February of 2015. The side effects of this treatment were not as aggressive as the previous treatment but I did suffer from tension headaches and excess acid in my stomach which led to heartburn and indigestion all the time. I felt really down whilst I was on the treatment but I did manage to work throughout. I was determined to maintain some sort of normality.

26. I completed the full course and was devastated when I was told that I had not managed to clear the virus. I had endured all of that for nothing. My devastation turned to anger and I have now been left with all of the side effects of the various treatments without any of the benefits.

27. Following the treatment, I still suffer from bouts of depression and I have some dark days. I just can't seem to get through the week as easily as I used to. I am lucky that my partner is very supportive and is always there for me.

28. It is [GRO-C] extremely upsetting that [GRO-C] about 2 years ago. [GRO-C]
[GRO-C]
[GRO-C] I could remember reading something about when Hepatitis C takes hold it turns your skin and the whites of your eyes yellow and I was naturally terrified. Alarm bells were ringing and I [GRO-C] to see the GP and he basically dismissed my concerns. A short while after this, [GRO-C]
[GRO-C]
[GRO-C]

29. [GRO-C]

30. The virus, combined with my Haemophilia, has also restricted my life choices in terms of the types of jobs I have been able to do.

31. I have not been able to have children for fear of passing the virus on.

Section 6. Treatment/Care/Support

32. I have never felt that I have been refused access or had to deal with any obstacles in relation to accessing medical or dental services.

33. However, **Exhibit WITN1538006** is a letter dated 26th January 1998 from M C Bishop, Consultant Urologist to Dr Dolan which states "*You mentioned that you would check his Factor IX sometime just before his admission. As you suggest we will, in view of his Hepatitis C problem, operate on him at the end of the list*". This shows that I was purposely placed last on the operation list as a direct result of being infected with Hepatitis C.

34. I have never been offered any counselling or psychiatric support as a result of my infection.

Section 7. Financial Assistance

35. I found out about the Skipton Fund via the Haemophilia Society and in or around 2011, following my separation from my wife, I reached out to them to seek advice with regard to my debts. They referred me to an independent financial advisor who provided a report for the Skipton Fund.

36. The Skipton Fund did not help me to clear my debts but instead they gave me a small amount of money in the hope that my debtors would accept that in full and final payment. However, this meant that I was then credit blacklisted which came with a wealth of further problems.

37. I also received the Stage 1 payment of £20,000 from the Skipton Fund but I am unsure as to when.

38. I applied for a few grants from the Skipton Fund. The process of applying was a complete nightmare, you had to jump through copious hoops and fill in numerous forms. It felt like a begging exercise. I literally had to expose every part of my life to them and then wait

patiently for the monthly committee meetings. Their decisions were arbitrary and unfair and I would conclude that the Fund was not fit for purpose. I have never felt so degraded in my entire life than when I had to engage and deal with the Skipton Fund. They tried to make you feel grateful for their help when in fact they were more worried about their own accounts than actually helping the victims of this tragedy.

39. I now receive the Special Category Mechanism (SCM) payments from the EIBSS in the sum of £1,500 per month. In order to receive this money I had to fill out a form, attend the GP and basically divulge a great deal about my life. I find it very depressing that I have to fill out a form to tell them how I fell and then justify this year on year. I was given this infection and yet I am made to prove things time and time again. This needs to stop.

40. The EIBSS also gave me the low level winter fuel payment but I appealed this and I now receive the higher level payment in this regard.

Section 8. Other Issues

41. I have never been part of any of the campaign groups. I never felt the need to reach out to them and I have dealt with my issues alone.

42. I want answers from this Inquiry. I want to know where it all started from and who made which decisions and why. I also want to know why the pharmaceutical companies have got away with their actions and I want to know why the consultants went along with it.

Anonymity, disclosure and redaction

43. I do not wish to apply for anonymity and I do want to give oral evidence to the Inquiry.

