

Witness Name: Steven Newby

Statement No.: WITN2233001

Exhibits: none

Dated: 19th August 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEVEN NEWBY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15th May 2020.

I, Steven Newby, will say as follows: -

Section 1. Introduction

1. My name is Steven Newby. My date of birth is GRO-C 1973 and my address is known to the Inquiry. I am currently employed as Sales Manager and run a sales team for a hazardous waste company, I have been in this role for the last three years. I am married to my wife Julie Newby and we have been married for eleven years. We have four children together, GRO-C who is nine, Olivia who is eighteen, Nicole who is nineteen and Liam who is twenty one. I intend to speak about my experience of becoming infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

2. I do not wish to be anonymous for with statement.

Section 2. How Infected

3. I was infected with hepatitis C during treatment for my haemophilia A, which I was diagnosed with at six months old. I would typically always be treated at the Haemophilia Centre at the Royal Infirmary Edinburgh in relation to my haemophilia, but was treated at the Sick Kids Hospital in Edinburgh as a child. It was Dr Ludlam that was in charge of my care during my time at the Royal Infirmary. I am unable to say exactly when I was infected but I was diagnosed around 1993, when I was twenty two years old, so I know it would have been before that date.
4. I have a Factor VIII inhibitor so in treating my haemophilia I have received Factor VII, Factor VIII, Factor IX and FEIBA blood products over the years. When my inhibitor was first discovered, I would often be treated with a combination of Factor VIII, Factor IX and FEIBA blood products, known as eradication therapy, as well as receiving them individually. The eradication therapy was an attempt to try and get rid of my inhibitor but that did not work. Eventually, the treatment I received that proved to be most effective was recombinant synthetic Factor VII which I have been receiving since I was fourteen or fifteen. I was one of the first people in the UK to receive Factor VII because of the presence of my inhibitor and because I am a Jehovah's witness and have been receiving that since it first became available. It is impossible to say which of these treatments led to me contracting hepatitis C but I would say that before I was nine years old, I would very rarely be taken into hospital for treatment. At nine, there was marked increase in the frequency and intensity of the treatment I started to receive so I think it is most likely my infection was contracted from that age onwards but it is impossible to say for certain.
5. I began to be treated even more regularly at age fourteen because around that time a GRO-C

GRO-C

GRO-C Dr Ludlam GRO-C

and among the arguments he made in favour of me continuing to receive the blood products, that ultimately infected me, he argued that if I did not receive them, that I would never walk again.

6. Neither my parents nor I were ever given any information about the risk of infection from receiving these blood products. During the GRO-C GRO-C my parents raised the question of the risk of infection and Dr Ludlam described the risk of me contracting an infection from the treatment for my haemophilia as "*infinitesimally small*".
7. I was diagnosed with hepatitis C around 1993, I cannot remember the exact date, during a routine appointment for my haemophilia at the Edinburgh Royal Infirmary. I cannot remember the name of the consultant that spoke with me but the appointment started as they typically would. He asked me how my day was, how I was getting on with my treatment etc. then he asked me in passing "*how are you getting on with your hep C infection?*" I asked him if he had mistaken me for someone else but he double checked my notes and said that I did have hepatitis C and he wanted to check how I was getting on with that. I told him that up until ten seconds ago I didn't know I had it. I was never aware of having been tested for hepatitis C before that appointment. Finding that out came as quite a blow but even after I was told, there was no help, support or even a conversation offered at all, I was just left to deal with things. He told me that there was information out there about hepatitis C and that I should look it up when I get a chance but that most people with the infection live long, full lives. When I looked up the infection myself I saw that some of the repercussions of the infection were life shortening or life ending and that was horrific to discover on my own. I had just married my first wife at the time and I was very worried about what I should do. I remember going home and crying that day wondering how long I had left to live.

8. I was given virtually no information whatsoever at my appointment. The only thing I was told was that it could potentially be life threatening depending on how it developed but symptoms might not develop for ten to twenty years. He told me that chances are I would live to a ripe old age and that most people don't have any issues with a hepatitis C infection. It felt like he was trying to downplay the whole thing. I think the doctor was embarrassed, I could tell that he felt he had put his foot in it. At one stage he even left the room for about twenty to thirty minutes and then came back, I don't think he was prepared for that conversation at all.
9. Nothing I was told that day was sufficient for me to fully understand or manage the infection.
10. The information about my infection definitely could have been provided to me earlier than it was. I was asked at that appointment how I was getting on with it, that means they must have had that positive hepatitis C result for quite some time. It was already in my notes and that doctor I spoke to presumed I had already been told.
11. The way I was told about my infection was almost cold, it was so nonchalant. It felt like the infection was minimised as much as possible to make me think that it might not even be a problem.
12. I was given no information about the risk of cross infection at the appointment whatsoever. I was married at the time and there was no mention of safe sex or caution around using the same toothbrushes, I was left completely in the dark.

Section 3. Other Infections

13. Sometime after the hepatitis C discussion, maybe around a year later, I found out I had the antibodies for hepatitis B at another appointment at the Haemophilia Centre at the Edinburgh Royal Infirmary. So at some point I had contracted hepatitis B and my body had managed to fight it off. I think it was a Dr Rosie that I spoke to and who told me about this secondary infection. I

was not given any time frame for when I had hepatitis B, only that I had it and it was gone, the infection seemed like a surprise to them as well. Just as with my hepatitis C result, at some point they had screened me for hepatitis B but I had never been informed that was being done.

Section 4. Consent

14. I have definitely been tested without my knowledge and consent because I was never made aware of the hepatitis C or hepatitis B tests being performed. I could not say whether I was ever treated without my knowledge, it's possible that could have happened when I was a child and not fully in charge on my care but it's hard to say for sure. When I was younger I would have to be restrained or tied down to a bed to be given treatment. I just didn't like the injections and the needles when I was younger. I was essentially forced to take my treatment when I was child, I would be restrained at the wrists and ankles and would have a pillow laid across my chest to hold me down. I would receive the injections in my feet or just anywhere they could manage to get a needle into me because of my refusal to receive these haemophilia treatments. Sometimes I would even get bleeds because of the restraints they put on me to treat other bleeds! I remember one instance where someone had grabbed my elbow so hard to restrain me, that I was actually in hospital to treat that for longer than I was to treat the initial bleed I had come in for. I was regularly assaulted when receiving my haemophilia treatment as a child.
15. I received treatment with Interferon and Ribavirin for around seven weeks to treat my hepatitis C but I had to stop because of the side effects of the treatment. I was not given adequate information about that treatment to prepare me for what I was going to experience whilst I was receiving it. They did not tell me about the horrific side effects that treatment would cause.
16. It would be hard for me to say whether I had ever been treated or tested for the purposes of research. I was never informed what the purpose of the tests

they performed on me were for, so it is possible some of them could have been for research.

Section 5. Impact

17. Initially, the mental effect of the infection was not knowing whether it was a life threatening situation or not, that was a huge strain on me. I was constantly worrying about whether my life was going to be cut short or whether I was going to be able to live the rest of my life with my children and my family. The strain and worry about those thoughts were a constant thing, every time I brushed my teeth, every time I woke up in the morning it was just always on my mind. That doubt and that fear was something that never went away.
18. Physically, the infection would cause bouts of fatigue and tiredness, it would make me feel overcome with lethargy a lot of the time. In my early twenties, I was working as a carpet cleaner and that fatigue affected my earning potential because there were days where I was so tired I couldn't really work. I would also often get night sweats and have a lot of trouble sleeping because of the infection.
19. I have not developed any further medical conditions because of my infection.
20. I was initially treated with Interferon and Ribavirin through the Royal Infirmary for my infection but I was only able to take that combination for seven weeks before I had to stop, the side effects were absolutely horrible. I started that treatment around the year 2000 but I could not give an exact date. I felt like that treatment was changing my personality, I was emotional, I was aggressive, and I was depressed. It felt like it was completely changing me as a person, I just could not continue with it. Physically, it felt like having a bad flu, it caused a lot of aches in my body and I just felt extremely unwell. Before I received the treatment, I was told that this was my best shot to clear the infection, but they did not tell me anything about what kind of effect it was going to have on me, none of those side effects were mentioned. They told

me that there could be some flu-like symptoms in the first week but if I took some paracetamol that should pass, however that was not an accurate description in the least.

21. I received another round of treatment in the form of Harvoni around four or five years ago. The treatment was a three month course and the treatment was successful. I had two tests following the treatment to confirm that the infection had been cleared, one after three months and another after six months and both tests confirmed that I had cleared the virus.
22. After the treatment with Harvoni that I received, I started to have significant problems with my memory. There are times where I have real problems with my ability to remember things. I would often forget that I had done something or even forget entire conversations I've had with people, it was quite scary. If it wasn't for my Wife, there are times I wouldn't be able to get anything done. It feels like you have been awake all night at times, simple tasks can become extremely taxing. Those problems with my memory probably started around four or five years ago and I feel like they've been getting progressively worse since then. I was told when was receiving treatment that the brain fog would get better once I had completed the treatment but it has not.
23. In terms of obstacles in accessing treatment, I would say that I waited a very long time to receive the Harvoni treatment. After my failed treatment with Interferon and Ribavirin, I was always asking what could be done to clear the infection and whether there were any new treatments in the pipeline that I could be treated with. Despite asking for years, I was always told I would need to wait and that there would probably be something in the next five to ten years but that didn't help me put it out of mind. I found out about the Harvoni treatment after speaking with Dan Farthing of Haemophilia Scotland who told me about the treatment and said I should push to receive it. I started to enquire about receiving Harvoni whenever I could at the Royal Infirmary and around a year later, I was offered the treatment. I don't know if there was pecking order for who received Harvoni first, people with advanced cirrhosis for example, but it felt like I waited a very long time.

24. I was offered absolutely no consultations or advice in relation to my infection from the beginning so it is very hard to say whether there could have been other treatment options available. I was not made informed enough to know if there were other options.
25. My infected status has meant that for dental work, they always have to take extra precautions. Other than that everything else relating to my treatment is done in hospital so my infection hasn't had any great impact on my treatment for anything else.
26. The infection impacted my family life on a daily basis. The not knowing whether I was going to live and the emotions tied to that doubt had a daily effect on my family and I. The worry of cross infection was a struggle as well, always having to think about what you needed to do if you got a tiny cut or making sure your toothbrush was well away from anybody else's. It was exhausting to think about all the time. My wife Julie and the kids knew about the infection and they would see the stories on the news about people with hepatitis and that would only make them worry more. There was a guilt that came with the knowledge that my family was dealing with this as well. My GRO-C GRO-C GRO-C. I am very lucky to have a very supporting wife and family now to help me through everything. The infection was a just a huge emotional toll and the thought of it never really goes away.
27. The infection also impacted my social life, there was some people you felt you couldn't tell about the infection. It wasn't that you didn't want to tell your friends, it was more that you didn't want it to become a big issue between you, so you kept it a secret. I just didn't want to be treated any differently and it created a bit of a distance between me and my friends in that sense.
28. There was a lot of worry and anxiety around the stigma of hepatitis C as well, you just felt that you didn't want anyone to know that you had it because people could just start looking at you differently. It's not that having hepatitis C necessarily put a label on you, but in a way it did and that's why

you felt the need make sure no one knew. There was one instance where our GRO-C actually phoned a helpline behind our back to see if the girls were actually safe to be living with us. That felt like a slap in the face, things like that make you feel almost dirty, like it's your fault somehow.

29. There would be times where I had to work less hours or work in less physical roles because of my infection due to the exhaustion it caused. Also, because of interrupted sleep and night sweats, I would wake up the next day without having properly slept and that just ensured the fatigue would carry on from day to day. Financially that would have an impact in that there would be times where I would need to take days off or days where I wasn't able to work for as long as I should have. When I did take days off they would always be taken as sick days because there was no way I felt I could tell an employer about my infection. I could not let something like that effect my professional life, there was too much stigma associated with it to be completely honest about my health. There have been jobs in the past that I have lost because of the amount of sick days I had needed to take. I would rather look for a new job than explain to my employer why I was taking all the time off and those gaps in employment had a financial impact as well. The infection just permeated my whole life really.
30. I think the biggest impact of the infection on my family and those close to me was the unknown. It was the not knowing how long I would be around for, whether I was going to die next year or the year after that. I know for Julie and the kids that must have been really tough. They would hear stories of people getting liver cirrhosis and dying not long after and I felt sometimes they would look at me and be wondering how long it would be before that happened to me as well.

Section 6. Treatment, Care and Support

31. I have not faced any difficulties in accessing treatment care or support as a result of my infection.

32. I have not been offered any counselling or psychological support as result of my infection. I think that is something that might have helped me if it had been offered. Looking back, it was all the doubts and the unknown questions that really did the most damage to me psychologically. If I was able to talk those things through with someone I might have been able to cope with it better.

Section 7. Financial Assistance

33. I received £20,000 from the Skipton Fund when it was first set up but I cannot remember the exact date of that. I also received £30,000 from the fund around four or five years ago. I can't remember how exactly I found out about the fund but I think it was just through word of mouth at one the Haemophilia Society meetings that I had attended. The application was a series of forms asking about the infection, things like when I had been infected and there was a form to give to the Haemophilia Centre to verify that I had been infected. I don't remember there being any difficulties in applying to the fund.
34. I receive a monthly payment of £525 from SIBSS as well and those payments started around two years ago. I found about SIBSS through Haemophilia Scotland, I think it was Dan Farthing that told us we could be entitled to something from the fund. The application for the fund was a self-assessment type form and I just put that I was moderately because I wasn't really sure exactly how to quantify what had happened to me. That was the only difficult thing about the application really, having to access yourself in that way. I would say applying to SIBSS was very straightforward though.
35. I would say that there is very little information out there for people who have been affected by this about the funding and financial assistance that is available. Right now, I could be sitting at home and be entitled to something that I am completely unaware of and that's because of how poorly advertised

the funds are. There is nowhere near enough information out there for people about what help is available to them. If I hadn't spoken to other people or gone looking for information myself, I wouldn't know where to start with getting help.

Section 8. Other Issues

36. I think my experience of what happened is a bit different to some others because I had to be forced to take the treatment that infected me, both because of religious reasons and that I didn't want to be infected. I just feel what happened to me was a slightly different scenario because I didn't want to receive blood products and I was fighting medical staff as much as I could when I was younger to stop them from giving me the treatment. From my point of view, the whole thing was dealt with incorrectly from the very beginning. I view it as incredibly fortunate that I did not contract HIV as well as hepatitis C but that doesn't change the trauma I have had to deal with because of this ordeal. The whole picture of what happened has left me feeling like an emotional mess, I still don't know if we will ever see justice for what happened. I'm hoping that this Inquiry will actually be able to make a difference.

Statement of Truth

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

Signed 
Steven Newby (Sep 1, 2020 15:02 GMT+1)

Dated Sep 1, 2020