

Witness Name:

GRO-B

Statement No.: WITN4675001

Exhibits: Nil

Dated: 26th March 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7 September 2020.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1966 and my address is known to the Inquiry. I work in the further education sector and have been employed by the GRO-B since 2014. I live with my husband, GRO-B: H and we have two children together.
2. I intend to speak about my husband and his infection with hepatitis C (HCV) from treatment he received for severe burns following an accident in the late 80's. In particular, the nature of his illness, how it has affected him, the treatment he has received and the impact it has had on our lives together. H has also provided a statement which will cover a lot of his story in greater detail than my own. (See GRO-B).

Section 2. How Affected

3. [H] and I have been married for 19 years and, over the course of our relationship, he has never been seriously ill or had any persistent health problems. He has had no surgery during this time and has always been in reasonably good health. Neither of us have ever used illegal drugs or have any tattoos.
4. [H] enjoys long-distance charity walks and in August 2019 he went on 30-mile-long walk that took him months to recover from. His legs were severely swollen for weeks afterwards, he was lethargic and generally unwell. It was around this time he started passing blood in his urine. I felt that something was seriously wrong and insisted that he went to the doctors.
5. The GP recommended some blood test be done. I usually open our post as [H] used to travel a lot with his work at that time. He was in Banbury when a letter addressed to him arrived from the hospital. It was a relatively blank sheet of paper with just a few lines of text. No explanation, covering letter or advice sheet. It stated – 'hepatitis C - positive'.
6. I called [H] straight away as I was totally confused. He was as stunned as I was and we were both very upset. It was an awful way for us to find out about his diagnosis. I knew nothing about HCV prior to all this, just that there was quite a lot of stigma attached to it. I always understood it to be associated with drug use so began to search the internet for information about the virus.
7. When [H] called the surgery for more information about the letter, they gave the impression that they should have told him in person or over the phone before the letter was posted but confirmed the diagnosis was correct.
8. We were both in shock for days afterwards and as there was no information or help from the surgery, we both researched hepatitis and

how it is transmitted on the internet. We found out that it can only really be caused by blood-to-blood contact so we had to think very hard to identify any instances where he could have got it? The only occasion where it could possibly have come from was in the late 80's before we met. [H] had an accident at work that left him with severe burns and needing an extended stay in East Grinstead hospital burns unit. [H] goes into much greater detail on the nature of this accident in his statement. We believe that he may well have needed a blood transfusion or plasma as part of his treatment following this accident. [H] is still in the process of obtaining his medical records in order to prove this.

Section 3. Other Infections

9. As far as [H] and I know, he has not been infected with anything other than hepatitis C.

Section 4. Consent

10. [H] covers his admission to hospital in detail in his own statement, including how he was largely unconscious for a significant period of time after his accident. This means that, if he did receive a blood transfusion during this time, he did not know that he was being treated in such a way and was, therefore, unable to consent to it.
11. [H] cannot remember being told that he was being tested for HCV. I know he would have told me had he known that they were testing him for the virus because of the potential implications for myself and our family. By implication, if he did not know this test was being carried out, he cannot have consented to it.

Section 5. Treatment/Care/Support

12. [H] began his treatment in April of this year. He will be able to provide more detail on the exact treatment that he is on. It consisted of a single tablet taken once a day.

13. The treatment has made him terribly ill. I will go into more detail on the impact of his treatment in Section 6, below.
14. All of [H] consultations and appointments have been conducted over the phone because of the pandemic and current Covid-19 restrictions. However, the standard of the care and support provided during these calls has been very poor. They ask him every single time if he's been taking his tablets and if he's been drinking? That's pretty much it. There is no advice, particularly no forward-looking advice about how to manage the virus and how to live with the consequences of it.
15. There has been no signposting to relevant resources and no advice on where to find help. I know that the NHS has been under great strain but it all seems so unfeeling. There has never been an apology for the way in which we were informed and the telephone consultations are just an opportunity for [H] to be interrogated about his lifestyle. He is made to feel like an alcoholic drug addict which is totally untrue. It has made him feel very depressed.
16. There have been many errors and last-minute changes to appointment and consultations. The administration of them has been awful. Yesterday [H] sat waiting for a telephone appointment for two hours, before ringing the doctor to find out what was going on? They informed him that the appointment had been moved to October but we hadn't been informed. A letter should have been sent out but as on many other occasions, we did not receive anything.
17. [H] has only completed his treatment recently but early tests indicate that he has cleared the virus. He has another test at the end September. We were obviously extremely happy to hear that he has cleared his HCV, but now worry about the extent of his cirrhosis. [H] doesn't try to hide any communication from me, a letter came recently that indicated his liver damage is severe. I have researched the stats he was originally given and it seems bad. The last stats he received indicated that the reading was slightly lower but it's still bad as far as I can tell. The

information I can find is very limited and again, highlights the problems with a complete lack of support from the hospital. The sheet of figures and data obviously means something to the Doctor but there is no explanation as to how you (as a patient) should interpret it or what any of it means.

18. The best help [H] has received is from the British Liver Foundation & Hepatitis C Trust. He isn't usually that chatty over the phone but he has spoken to them at length and more importantly, at ease. They have taken the time to listen, offer advice and reassure him that some people can survive it. They have given him practical advice and answered his questions. I really can't praise them enough.

Section 6. Impact

19. [H] diagnosis and subsequent treatment has had a massive impact on our lives. When I opened that letter, I was shocked, saddened and initially convinced that it was terminal. The manner in which we found out was appalling and I hoped that the hospital had made a mistake until [H] called them and the diagnosis was confirmed.
20. [H] wanted myself and our two sons to get tested for our peace of mind. No tests were offered to us but I arranged mine with my GP Surgery: [GRO-B] in [GRO-B] without a problem. It was however, quite hard to explain that my husband was HCV positive and I wanted a blood test to confirm if I was too? I recall being very upset at how overwhelming it all was. The nurse said to me, "I'm sure if you had it, you would know." But [H] had it for years and didn't know.
21. After a five day wait, our results came back negative. A huge relief for us but sad that they had not detected [H] Hep C earlier as he has had numerous blood tests over the years and we both thought a blood test would look for anything that was not correct. The Doctor has advised that is not the case, all tests are looking for something specific.

22. Having thought back over the years I have spent with [H] and thinking about possible signs of infection, there are several symptoms he has suffered in the past that I now believe may have been a result of his HCV. A prime example are his chronic nosebleeds. He can have these quite often and it is like someone turning on a tap; it gushes out. He has had the veins in his nose cauterized several times over the years but the nosebleeds are back within a day or two. Reading about it now, I think this might have been linked to his HCV.
23. He has often been very tired and fatigued over the years and has suffered with bouts of depression at times.
24. The treatment [H] has undergone for the Hep C comes with a variety of side effects. He has developed persistent tinnitus. Sometimes he can't hear me at all and has this constant buzzing in his ears. He suffers from terrible headaches and unbelievable fatigue. He can sleep all day and night; his joints ache and he has had problems with toothache. Dentists are currently only taking on emergency cases and [H] is worried about going because he will have to inform them of his HCV.
25. He can sometimes suffer with 'brain-fog', a sort of distanced confusion. He is usually the sort of person that only needs to go to a place once and then he'll remember exactly how to get there. But nowadays he'll find himself taking us to completely the wrong place. We were recently going to my parents' house and he started driving off in the opposite direction. I don't think he ever had these lapses in concentration before his treatment, but if he did, it has certainly got worse since he began taking his tablets.
26. [H] has always been a dreadful sleeper. When we first got together, he'd have bizarre nightmares and would sleepwalk regularly so I can't say whether his HCV or treatment has had much of an impact on his sleep as it is already quite irregular.

27. Even now that [H] treatment has concluded, many of these symptoms persist. He still has the tinnitus, the loss of concentration and generally remains quite tired and lethargic.
28. It is distressing to think that [H] has had this infection for so long. We worry a lot about how much damage it has done over the years and I fear for the future together. We have always worked hard and over the last few years have finally started to feel like we can look forward to retiring a bit early and enjoy ourselves but all of a sudden, there is a huge question mark over our future plans. He gets so exhausted and it hangs over any plans we make. It's very sad that [H] may never be well again.
29. There has also been an impact on [H] working life. He was furloughed for a short period in March and then worked from home until August, when he returned to the office. He had a good set up at home and I don't think it had a huge impact on the way he works. His boss has been understanding about the illness and has allowed him to sleep for a few hours during the day. At the start of August when he returned to work, I think found it hard to keep his concentration at first. He does a lot of number crunching and has found it difficult to focus at times.
30. [H] advised his boss of his Hep C shortly after he was diagnosed. They had a chat recently and his boss felt [H] had gone back to work too early. They agreed that he will work from home until Christmas and then review the situation. I think [H] is happy about this.
31. The whole thing has had a definite impact on our marriage. When [H] was first diagnosed, he had these awful feelings about being unclean and thought that he needed to stay away from me. He'd insist on sleeping downstairs on the sofa, having his own towels and washing his own clothes. He wouldn't want to be close to me. I went along with it initially, before realising it made no sense. We have been married 19 years and I haven't been infected. He still has these feeling of being

unclean but is slowly coming to terms with it. I guess, there are no rules for this sort of thing and everyone deals with it differently. We are united in our little bubble.

32. Personally, I have moments where I can get quite emotional and anxious, wondering how things will unfold. There have been many sleepless nights and sometimes I can't stop thinking about the long-term implications. He's always been such a strong man; it is hard to see him brought down by this horrible illness. All I want is for him to be alright because I love him.
33. In terms of the wider family, [H] has never seen a great deal of them. I don't think that there has been as big an impact as there has been on [H] and I. He isn't particularly close to his external family and we haven't told them he is ill. [H] is embarrassed and just devastated to have HCV and has asked me not to tell anyone. I wouldn't have anyway.
34. Telling our sons was difficult, but there hasn't been a huge impact on them. Our eldest son was back home from university seeing friends when lockdown began and has only just been able to return in July. I don't think that he worries about it too much. Our youngest is 20 so we don't see much of him, but I think he manages ok. As long as he can see that dad is still there in his favourite chair, he's alright. The initial worry that they both had has subsided – they didn't understand and were obviously worried that they may have it themselves. Now that they know a little more about it and have had a negative test result themselves, I think they are fine.
35. Financially, there hasn't been a massive impact on us. We have mortgage insurance and have both been able to continue working throughout the Covid crisis.
36. Covid-19 has also put a huge restriction on social interactions as well, so there has been little noticeable impact on our social lives. We both have our own friends and enjoy exercising together.

Section 7. Financial Assistance

37. I am aware that [H] is in the process of applying for financial assistance from a scheme set up for this purpose. He is waiting for some forms to be completed by Dr Shah, his consultant. He sent these forms off sometime in June and has inquired about them several times, but Dr Shah [GRO-D] and has not had a chance to complete them yet.
38. [H] was planning on bringing this up with the nurse that he was supposed to meeting yesterday, but has now been belatedly informed that this meeting has been moved to October.

Section 8. Other Issues

39. The whole thing has caused [H] and I a great deal of stress and, although he now appears to have cleared the virus itself, the extent of the damage to his liver casts a huge shadow over our plans for the future.
40. I have also been tremendously disappointed with the response from the NHS. I appreciate that this has come at a time when the health service is under immense pressure but administration has just been awful and I can't see that the current situation is an excuse for it. Not only were we informed via a letter with no explanation or offer of support, the subsequent appointments have to my mind been poorly organised.

Statement of Truth

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

Signed [GRO-B]

Dated 26th March 2017