

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3244001

Exhibit: WITN3244002

Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B and I live at GRO-B.
GRO-B. I am married to GRO-B.
GRO-B: H We have been married for GR years. We have three children GRO-B.
GRO-B. I am currently a full-time mum, in the process of training for GRO-B.
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2009 as I have also been infected with Hepatitis C, which I contracted through H. I am aware that my husband has also provided a statement to the Inquiry under GRO-B.
3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

4. I have been infected with Hepatitis C as a result of my relationship with my husband [H]. We met in around July [GRO-] and I was infected with Hepatitis C by him sometime between this date and my diagnosis on 20 November 2018.
5. My husband was born with a mild Haemophilia B and believes that he was infected with Hepatitis C aged [G] when he was given Factor IX concentrate (FIX) during a dental procedure.
6. I am aware that [H] spoke to his dad, who clarified that the doctors did not inform him or [H]'s mother about the potential risks associated with being treated with blood products.
7. As a result of the one treatment [H] had in [GRO-] he contracted Hepatitis C. This is described in more detail in his witness statement.
8. I was only tested for Hepatitis C after my husband was found to be positive in November 2018. He came about this knowledge by a complete accident. We decided to have our [GRO-B] tested to check whether she was a carrier of Haemophilia, as [GRO-] does [GRO-B] and we realised that she bruised surprisingly easily.
9. We took our [GRO-B] to the [GRO-B] to have her tested on 8 November 2018. When we arrived for that appointment, Dr [GRO-B] asked to see [H] first. I found it rather strange. He later informed me that she suggested that he should be tested for Hepatitis C. It was done in a very casual way, so he did not think anything of it. He certainly was not worried about it, as it seemed as more of a routine test than anything serious. I had no idea that he was tested for Hepatitis C at the time.

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10. Dr [GRO-] called [H] by phone on our [GRO-B] birthday, which was [GRO-] [GRO-B] 2018 and informed him that he had tested Hepatitis C positive. He was in total shock. [H] asked her how likely he was to have the Hepatitis C virus in his blood, to which she responded "*highly likely*". That was another shock to us, especially since they had time to have him tested since [GRO-]. I did not know about it until the next day. [H] wanted me to enjoy our [GRO-B] birthday, so he kept it to himself, in order not to worry me. I was in shock when he finally told me about it.
11. I am concerned and angry that our awareness of his infection only came about because we decided to get our [GRO-B] tested to see if [GRO-] was a carrier of [H]'s blood disorder. We were so surprised when they even mentioned testing [H] for Hepatitis C. We were not aware that he was at risk. He is [GR] years old and he only had one transfusion when he was [G]
12. [H]'s mental health was affected greatly by the stress and worry resulting from his infection. He felt guilty and he was worried that he might have passed the virus onto me and our children. I recall that [H] and the doctors told me that the chance of him passing it onto me or our children were slim, but at the same time I am aware that even mosquitos can pass it on. At the time I felt like as long as there was any chance, even the most remote, that I should have us tested as well.
13. I had my test done first at [GRO-B]. I told [H] that if I did not have Hepatitis C then the children would not have it either. It was very difficult for me to have the tests done, as not only was it stressful to think that I might have the virus, but also I am terrified of needles. It took a lot of effort from me to do it.
14. I received my results on the same day as [H] had his consultation at the hospital about his treatment. I received a phone call from my GP who told me

that I was Hepatitis C positive. He said that he was very surprised by the results and that he was very sorry.

15. At the time, I had to deal with my own feelings about this, as well as having to manage [H]'s extreme distress. I cannot stress the decline of [H]'s mental health state at this time and how hard it was for me to try to manage.

16. I do not know when or how exactly I was infected. It could have been at any point during our relationship: from when I met him until when I was tested for Hepatitis C on 20 November 2018. I could not have contracted it elsewhere, as I had never taken intravenous drugs, in fact I would be the last person to do so, as I am terrified of needles and blood. I had also never had any blood transfusions. I have only [GRO-B] but I do not think that I would have contracted it then. Therefore, the only source of the virus could have been [H]

17. I ended up going to [H]'s consultation with Dr Joseph with him on 3 December 2018. I felt that Dr Joseph ended up being incredibly rude to us. He treated us as if we were unreasonable, said that we were harassing him, and putting him under pressure. However, he was very confident about the treatment. We asked whether we could start the treatment at the same time to save time. He eventually agreed to it.

18. Right after our initial meeting with Dr Joseph, we were called into another room by a nurse called Anna, who worked alongside Dr Joseph. She was great; she gave us all the information about Hepatitis C and about the treatment; so that we had a better understanding by the time we left the hospital.

19. We also had a fibroscan at [GRO-B] on 3 December 2018, as they do not do it in [GRO-B] where we live. Thankfully, our livers have proved to be in perfect shape and my fibroscan result was 4.6. Miraculously, [H]'s liver was in an amazing condition, despite having the infection for over 4 decades.

20. We started our Hepatitis C treatment on 11 January 2019 which I believe it consisted of Harvoni tablets. The treatment lasted for 8 weeks, with regular blood tests to check our viral load. We finished it on 25 March 2019. Originally, my viral load was higher than [H]'s, but I managed to clear it faster than him. Our latest blood tests on 17 June 2019 show that we have both managed to clear the virus.

Section 3. Other Infections

21. I am not aware of [H] or myself contracting any other infection, as a result of him being treated with contaminated blood products.

Section 4. Consent

22. I do not believe that [H] or I were treated or tested without our knowledge, or for the purpose of research. I was aware of all of us being tested for Hepatitis C.

Section 5. Impact

23. [H]'s infection, and particularly the psychological effects that it had on him, affected me greatly. Generally, I am quite an open person and the way I deal with stress is by talking about whatever is bothering me, but in this case I had to respect the fact that [H] did not want anybody else to know about it. It was extremely difficult for me, because I felt like I had to mask my feelings and worries to protect our children, who also did not know about what was happening. I also felt like I had to hide my feelings to prevent [H] from feeling even more guilt and worrying about me.

24. Since we were not offered any counselling and [H] was in such a bad mental state, I ended up taking a role of a counsellor, trying to support [H] and motivate him, whilst also making sure that our children were fine. When he was particularly poorly I did have our children coming up to me and asking what was

wrong with Daddy, and I had to lie to them. I particularly did not want our children to know about what was happening, in case they became as paranoid as [H]. I kept on saying to them that [H] was stressed out because of his job and that the tests that they were having were to do were connected with research relating to Haemophilia and genetics.

25. [H] then became even more concerned after I was tested Hepatitis C positive. He was worried that our children could potentially have it. It got to the point whereby it was ridiculous and he was hysterical, so we had to have them tested to clear any doubts. We took them to [GRO-B] just before Christmas 2018. They were [GRO-B] and [GR] years old at the time. They did not understand what the tests were for, and it was very difficult because [H] still did not want anybody to know about the infection, including our children. He was extremely stressed out and anxious. I tried to keep him as calm as possible and reason with him that there is a treatment and that we would get through it. Thankfully all of our children tested Hepatitis C negative.

26. Getting our children tested was a very stressful time. The anxiety that we had to endure while waiting for their test results was horrendous. Having to put the children through the testing and having to think of what to tell them regarding the need for these tests was also very difficult for me, as their mother.

27. I always tried to explain things to [H] in a logical manner. Before we found out that I had Hepatitis C as well, I would say to him that even if I have it, there is a treatment to cure it and that the treatment is not horrible, but he was completely unreasonable at the time. He was so depressed and was talking about suicide. I couldn't talk to him rationally and I couldn't reassure him.

28. I am not certain how my Hepatitis C infection has affected me on the physical level. I do get tired very easily, but at the same time being a full-time mum of [G] children is also very tiring. It is hard to distinguish between what is normal and

what is an effect of the virus. All we can say is that we have been feeling a certain way for a certain amount of time.

29. Overall, I have been dealing with depression and tiredness, which I think might have stemmed from or be aggravated by Hepatitis C. I first began suffering from depression in around June [GRO-] which was about 13 months after [H] and I met. I wonder whether I could have been infected by then and this was a symptom of the Hepatitis C.

30. I saw my GP again in 2009 and began taking medication for depression, as described in the attached letter dated 9 January 2009 which is exhibited at [GRO-B]. I am still taking 150mg Sertraline a day.

Section 6. Treatment/Care/Support

31. We did not have any problems getting our treatment.

32. We were never offered any counselling. I do think it would be of help, as I ended up being [H]'s counsellor, when I think a professional should have stepped in. I feel counselling would have benefitted [H] as he was so irrational, and needed support from a medical professional reassuring him too.

33. I also think that it would have been useful for me, as I had nobody to speak to about what was happening. I had to put a brave face on to support [H] whereas I was worried about the state of [H]'s liver after having hepatitis for over [GR] years.

Section 7. Financial Assistance

34. The England Infected Blood Support Scheme (EIBSS) payment plan commenced on diagnosis. My husband has had Hepatitis C, unknowingly, for [G] years and we have been married for [GR] of those years. He should have been informed

many years ago. The scheme for regular monthly payments started in April 2016. Surely, we should both be eligible for all these payments.

Section 8. Other Issues

35. H was told he was infected on our GRO-B over GRO-B after he contracted the virus. I think it is unacceptable. The doctors should have contacted him to have him tested decades ago. The context in which he was eventually tested was accidental and it makes me wonder whether we would have ever found out about our infections if it was not for us having our GRO-B GRO-B checked for Haemophilia. It was a traumatic experience for all of us, and we still do not have answers as to why it took so long before H was tested.

Anonymity, disclosure and redaction

36. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

37. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed GRO-C

Dated 24.09.19

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Medical Chronology

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the statement)

1982	Febrile convulsion
1984	Febrile convulsion.
11/4/1984	Prescribed Epilim 100 mg tds
4/9/1987	letter Princess Margaret Hospital to CP. She is now 5½ and I think we should slowly discontinue her Epilim, which is in fact not a big dose
6/7/1990	Elipim stopped 'some time ago'
12/1/1998	inducing vomiting 1 year
1998	Anorexia Nervosa
12/1/1998	Psychiatric referral to GRO-B
21/1/1998	letter from GRO-B to clients mother offering assessment appointment 24 February 1998
7/1/1999	letter from GRO-B Adolescent Unit to GP. Mentions 2 year history of anorexia
5/6/2000	letter from GRO-B Adolescent Unit to GP. I am pleased to say that GRO- has continued her battle against Anorexia.... I have now concerns about GRO-s physical or emotional well-being at present
23/6/2003	National Health Service Call Report. Attended WIC today very distressed, has a long term history of depressive illness. Is voicing suicidal tendencies is pregnant. Referred to emergency GP appointment
23/6/2003	seen in GP surgery with husband. V low, tearful 2/52. No precipitating life problems 25/40 ?hormonal. Not suicidal. Supportive husband works from home and can be with her. Refer counselling. Pt to contact Cathy MW mane for further support: she clearly will be at higher risk of PND. Coding details: Endogenous depression
GRO- 2003	Normal delivery boy
1/12/2004	GRO- has needle phobia, requesting emla cream

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- 21/12/2004 Swindon & Marlborough NHS Trust – Dept of Microbiology. Antibody / Ag HIV 1+2 Negative by AxSym ... Hepatitis B surface Ag test Negative by AxSym
- GRO-1**/2005 Normal delivery boy
- 23/3/2007 letter from Swindon Primary Care Trust to client. As you know you have been referred to counselling / psychology service by your Doctor. GP notes. Quote low, has episodes of low mood since she is 15 years old but never for 5/12
- 10/8/2007 GP notes. H/O depression. Has been on antidepressants for 6 months. Feels much better now but gets very drowsy. Children age 2 and **GRO-1** 4.
- 11/9/2007 GP notes. H/O depression. Does not feel ready to discontinue SSRI, coping well at work, r/v decision in spring. Escitalopram 10mg 28 tablets 1OD
- 9/1/2009 letter GP to whom it may concern – summary of notes with regard to depressive illness
- GRO-1**/2011 daughter born
- 7/1/2012 GP repeat script for sertraline 100mg
- 4/3/2015 GP completed event insurance claim form due to migraine. Previous migraine attacks 28/9/2011 & 9/7/2013
- 19/11/2018 GP record 'came in for bt (blood test) with me ref husband with hep c'
- 20/11/2018 08:24 GP Pathology request. Hepatitis C Antibody
10:22 Hep C confirmatory tests. Ref lab Hep C antibody test: Confirmatory EIA POSITIVE. Hepatitis C PCR qualitative: POSITIVE. Consistent with active HCV infection. Please repeat to confirm. Recommend referral to an appropriate specialist for further assessment / treatment if active infection is confirmed. Consider requesting HCV genotyping. Please ensure hepatitis A and B immunity status is known and vaccination given if needed. If obtaining a confirmatory sample is not feasible, referral should not be delayed
- 28/11/2018 GP Microbiologist lab rang with test result – Test came back Hep C positive
- 29/11/2018 GP History: Advice about investigation results (XaAsY) advised that her Hep C antibody result is -ve. PCR awaited. She is understandably more

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concerned for her children and want them screened. She will speak to Hep C nurse in Oxford

- 3/12/2018 letter Dr Moby Joseph to GP. She accompanied her husband to my clinic today. **GRO-** got her blood test through the Oxford haemophilia clinic along with her children. Thankfully, her children tested negative for HIV, hepatitis B and C. **GRO-** herself was not that fortunate. She tested positive for hepatitis C antibody and she confirmed to me in clinic today that she is PCR positive. From clinic today, I have arranged a number of blood tests on **GRO-** to specifically test for genotype, viral load, liver function tests and fibrosis markers and also an ultrasound scan. If the investigation results come back in time, we will be able to process her MDT proforma along with her husband so we can put them on treatment together. I would be grateful if you could make a formal referral to me
- 3/12/2018 Fibrosan screening. Baseline viral load/ HCV RNA 152253 IU/ml. Non-cirrhotic, Genotype 1A, Treatment Naïve. 1st line (most cost effective) Sofosbuvir 400mg/ Ledipasvir 90mg OD for 8 weeks (NICE TA 363); NO RIBA. No interactions expected
- 12/12/2018 letter GP to Dr Joseph
- 19/12/2018 GP call from Sue, Dr Joseph's secretary. Need to put referral on e-RS, she will pick it up and book appointment with patient
- 16/1/2019 GP attends for medication review ... Sertraline 150mg, long term. Low mood and anxiety. Feeling OK. Not currently needing therapy. Work OK. Helps with husbands business... Plan: Meds reviewed and reauthorized
- 21/2/2019 letter from Hepatology, Great Western Hospitals to GP. This lady is now four weeks into treatment of Hepatitis C virus. I saw her recently and she reports no side effects and I am pleased to say that she has been compliant with the regime. Her viral load is now not detected.
- 25/3/2019 letter from Hepatology, Great Western Hospitals to GP. This lady is now at the end of the treatment for hepatitis C virus. I have seen her recently and she reports no side effects and I am pleased to say that the virus is not detected. We cannot be sure of sustained viral response until a negative PXR test three months after completion of the treatment.