

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN0096008

Exhibits: WITN0096009

Dated: 20/12/2022

INFECTED BLOOD INQUIRY

SUPPLEMENTARY WRITTEN STATEMENT OF GRO-B

I provide this supplementary written statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 26 October 2018.

GRO-B, will say as follows: -

Further to my previous statement dated 08 March 2019, and my addendum dated 17 April 2019 regarding my infection with HCV, I wish to add the following: -

I am aware that my mother GRO-B GRO-B and my sister GRO-B: S

GRO-B: S GRO-B have provided statements to the Infected Blood Inquiry.

I was in attendance when their statements were made. During the process, I recollected additional information which I had either not included in my first witness statement or addendum statement, or has since come to my attention after the point such statements were made.

Section 2. How Infected

1. In paragraph 5 of my witness statement dated 08 March 2019, I stated that I originally believed that I was infected with HCV in 1989. This was as a result of

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contaminated cryoprecipitate I had received in 1989, after I haemorrhaged following an operation at The Royal Victoria hospital, Belfast to have my tonsils removed. Also, after reading my medical notes, I now believe I may have been infected before this point in time. In a letter as part of my notes, Dr Mayne makes mention that I was the subject of blood product treatment before 1987. This letter I have already submitted to the Inquiry and is shown as **Exhibit WITN0096003**

2. Furthermore, since making my statement, in 2019, my mother **GRO-B** has gained information from Doctor **GRO-D** at Belfast City Hospital, Lisburn Road, Belfast, BT9 7AB, about a database run by the Haemophilia Society. This database contains details of all blood and blood products administered under the National Health Service ("NHS") from 1992 onwards and includes details of the recipient.
3. A short while after, I decided to get in contact with the Haemophilia Society to determine whether I could gain access to this database. I provided them with my personal and contact details. I was told that I would receive my results via the post.
4. When I received my results from the haemophilia database, it showed that I had received blood products, Factor V111, prior to 1988, ruling out my operation in 1989 as a possible source of infection. (**See page 10 and page marked 'Hep C 2018' of Exhibit WITN0096009**)
5. It is now my – and my family's belief, that I was infected in 1983, as a result of blood products I received at Royal Victoria Hospital for sick children, 274 Grosvenor Road, Belfast, BT12 6BA, following a suspected appendicitis procedure when I was eleven years old. Up until the tonsillectomy procedure in 1989, this was the only occasion on which I had received blood products.
6. If it was not for the Haemophilia Society database shedding new light on the point of my infection, I would still to this day be unsure of the likely true cause of my infection, despite the letter from Dr Mayne. The database provided corroboration.
7. It is really strange. Even though I was quite young as I can remember being in a bed on the right-hand side of the ward and there being a room, all glass, in the

middle of the ward and I was wheeled in there in my bed and I remember the needle being put into my arm for the drip. I also remember that the pain went away. When my mum and dad got back with my green dressing gown, pj's etc I can recall mum asking about the drip and me saying to her "they made me feel better with it and the pain had gone away" or words to that effect.

Section 3. Other Infections.

8. At paragraph 13 of my witness statement dated 08 March 2019, I stated that in 2006, I received a letter which notified me that I was at risk of having contracted vCJD due to blood products I had previously received.

9. When my mother was made aware of the Haemophilia Society database in 2019, we received results not long after. This has confirmed there was a risk that I received a batch of blood products that was contaminated with vCJD. This record shows that I was informed of the risk in 2004 and assessed in 2006 by Dr GRO-D. That is not my recollection. I first found out about this possible risk when I received the letter in 2006. Both my mother and sister also received letters the same year. **(See Exhibit WITN0096009, page 09 marked 'Patient vCJD Data')**

10. When I found out that I was at risk of having contracted vCJD, I thought that this was just another thing to add to my list of infections and conditions. I have had so much go wrong with my health due to my HCV, I almost switch off from it now. No medical professional has ever contacted me directly about the possibility of being infected with vCJD or about any precautions I should take or possible treatments available.

Section 5. Impact.

11. In 2018, I started to notice that I was losing my vision. If I was to look at a person, I would be able to see the outline of a face, but I could not see the detail. I thought that my eyes may return to normal after a while. However, this was not the case.

12. I was referred to an eye specialist at The Royal Victoria by Specsavers. At a face to face consultation with the specialist, I told him about my HCV, and the treatments I have received. This being Interferon and Ribavirin. He told me that as soon as he heard that I had been treated with Interferon, he thought this was the cause of my vision impairment. I gained the impression it was something he had seen before.
13. Since this point, my eye specialist has backtracked on this original statement. When I questioned this, he stated that the Royal Victoria Hospital has since told him that it is not a known side effect of Interferon treatment.
14. In 2019, my mother gained a second opinion from Doctor GRO-D at Belfast City Hospital. He told her that there are a large number of long-term side effects of Interferon treatment, which are only recently being brought to light. These side effects were not confirmed before this point.

Section 8. Other Issues

15. Between paragraph 23 and 24 of my previous written statement dated 08 March 2019, I had stated that in 2012, I was told by Doctor GRO-D at Belfast City Hospital, that I had grown out of my Von Willebrand's Disease and that they had made me all better. As far as I was aware, you could not grow out of a condition that you are born with, and is passed through the hereditary line. If you are born with it, you die with it. This made me so cross and upset to think I may not have needed all of the blood products I had been given and how my family have been told they all have grown out of Von Willebrand's in the 1 year.
16. Therefore, later in 2012, I decided to get a second opinion on whether this information was true. I got in contact with the Haemophilia Society in London over the telephone. When the lady answered, the name of whom I cannot recall, I recounted the information that I had previously been told about my Von Willebrand's Disease. She stated something along the lines of "as far as I am aware, I did not know this was possible, where did you get this information from?" I replied stating that I had received this information from Doctor GRO-D at

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Belfast City Hospital. After this, she placed me on hold to get a second opinion from her superior.

17. I was on hold for ten minutes. When she returned, she stated that she was in fact mistaken, and what I had been told was true. It is possible to grow out of your Von Willebrand's Disease.

18. After this, I had an appointment with Doctor Morgan my Gynaecologist at Antrim Area Hospital, Bush Road, Antrim, BT41 2RL. I had previously been told that I needed to undergo a hysterectomy. However, due to my Von Willebrand's, I was not able to undergo this operation due to the risks involved. He had told me that I had a fifty percent chance of dying on the table, which was too great a risk for me to take.

19. When I then told him what Doctor [GRO-D] and the Haemophilia Society had told me, he laughed. He said you cannot grow out of Von Willebrand's Disease. At a later appointment he chuckled when he read a confirmation he had received in writing from Doctor [GRO-D] to that effect. Again, this has already been submitted. **(See Exhibit WITN0096005)** I have still not had the operation to this day, and Von Willebrand's has not been taken off my medical records.

20. Any Doctor I have told agreed that it was not possible to grow out of a hereditary condition. Are Dr [GRO-D] and the Haemophilia Society mistaken? or are they covering something up? I cannot pass comment to that effect but the question eats away at me. How did my family all grow out of Von Willebrand's in the same year?

21. About 4 or 5 weeks back in May 2021 I saw Dr [GRO-D] at an appointment. I asked him outright about my mum, [s] and myself; Do we actually have Von Willebrand's? He simply replied that we had "bleeding disorders". Then, on the 8th of June I underwent an endoscopy procedure at [GRO-B] hospital. I asked the doctor carrying it out whether I could grow out of the disease as I had been informed. His reply was "How can you grow out of something hereditary?" There does not seem to me to be any medical consensus about our condition and it is far from reassuring for me or my family.

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22. For me, when I think of my HCV, I assume it will always be there. Lingerin in the background waiting to rear its ugly head. I believe someone up there, in another world, does not like me very much. I have not had much luck with regards to my health throughout my life.

23. My mother, father, and myself have a running joke between us that I am going to the grave with them. My mother and father have since bought a grave in the local graveyard, so that when I die I can be alongside them. A grave for three people. I just wish I could get some proper answers that would give me hope that I will get to live a full enough life, for the sake of my two sons and my husband who are everything to me. I don't think I would be here today if it was not for the love and support of my family, who have been there for me every day of my life. And for that I thank them with all my heart.

Statement of Truth

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

Signed _____ **GRO-B**

Dated _____

Table of Exhibits:

Date	Notes/ Description	Exhibit number
30.10.2019	Haemophilia Society Database Letter	WITN0096009