

Witness Name: **GRO-B**

Statement No.: WITN0096001

Exhibits: WITN0096002-5

Dated: 8/3/2019.

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

I, **GRO-B** will say as follows: -

Section 1. Introduction

1. My name is **GRO-B** (nee: **GRO-B**) My date of birth is **GRO-B** **GRO-B** 1972. My address is known to the Inquiry.
2. I am registered as disabled and am unemployed. I had to give up work in 1994 due to my deteriorating health after contracting Hepatitis C in 1989.
3. I intend to speak about my infection with Hepatitis C through the use of blood products. In particular, the nature of if my illness, how the illness affected me, the treatment received and the impact it had on me.

Section 2. How Infected

4. I was diagnosed with Von Willebrand disease, which is an inherited blood disorder disease. GRO-C
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5. In 1989 I had my tonsils removed and two weeks later I haemorrhaged and had to return to hospital to be given cryoprecipitate; I was assured this was safe and ok to be given. However, after reading my medical notes I believe I was infected before this – I cannot be certain when I was infected.
6. Approximately six months later I started to feel unwell; I had no energy with constant tiredness, felt a weakness in my body and joints and was unable to sleep. This resulted in my having to use my annual leave as sick days off instead of holidays.
7. After investigations by haematologists I was diagnosed with pernicious anaemia by Dr Jones at the Royal Victoria Hospital in Belfast and Dr Mayne, Head of Haematology at Royal Victoria Hospital. Additionally, they diagnosed me with myalgic encephalomyelitis ('M.E').
8. In 1993 I was stopped in the corridor of the Royal Victoria Hospital on my way to my haematology appointment by Dr E Mayne who asked how I was feeling. I told her I was no better and she replied "if it's not M.E., it must be the Hepatitis C".
9. This was the first I knew of Hepatitis C, let alone that I had been tested for it. Dr Mayne then persisted to tell me that this was just a little virus and there was nothing to worry about.
10. I have recently been able to get a hold of my medical records from my GP. I had to tell them that it was for my own records, my own purpose and nothing else – I did not tell them anything about the Inquiry.

ANONYMOUS

11. I have seen in my medical records that my treating doctors knew of my Hepatitis C diagnoses since 1987 but I was not told until 1993. As previously stated, this was whilst I was under the care of Dr Mayne and Dr Jones at the Royal Victoria Hospital and it was Dr Mayne who told me about the Hepatitis C in the hospital corridor.

Section 3. Other Infections

12. Throughout my life, I have had numerous health problems. I have now been diagnosed with chronic fibromyalgia, early menopause, bowel paralysis, arthritis, eye sight loss, insomnia, basal cell carcinoma, chronic fatigue syndrome, allergies, prolonged bleeding and gynaecology difficulties. I need a hysterectomy but they refuse to carry out the operation as I was told I would have a 50/50 chance of surviving, due to my complicated health history. Nobody can tell me these problems are due to my Hepatitis C diagnosis or are side effects of the treatments - Interferon and Ribavirin – that I received for Hepatitis C.

13. In 2006 I received a letter to tell me that I was at risk of vCJD due to blood products. I have not received any further information at this stage regarding vCJD.

Section 4. Consent

14. The first I knew of my Hepatitis C diagnosis was in 1993. I confirm that I did not consent to being tested for Hepatitis C.

15. I had to give consent to the treatment for Hepatitis C but was told they didn't know a lot about the side effects. When I asked would I still be able to have a baby I was told they didn't know; this is why I decided to have my son prior to treatment.

16. With regard to the blood products, my mother and father signed the form saying that they would consent to me receiving cryoprecipitate as a last

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resort. I also told the hospital to only give me a cryoprecipitate if I was in a life threatening condition. Looking back now I think they gave it to me too easily, I think they just thought 'she's in pain, let's get her treated and send her home'; I think they just wanted to free up a bed. They wanted to give me a blood transfusion but I refused this treatment.

Section 5. Impact

17. Due to health deteriorations I had to give up work in 1994. This was devastating as I was a fully qualified Book Binder with an excellent wage, a job I loved and excelled in with great promotional opportunities all gone! Through no fault of my own!
18. I proceeded to have my son in the Royal Victoria Hospital maternity wing in 1995. I was given my own room, bathroom and a hazard sign was placed on the outside of my doors. Additionally, my bedding, cutlery, plates etc. were put in hazard bags after use. My son's bedding, bottles, nappies etc. were also put in hazard bags even though he had not been tested at this point. Furthermore, I was not allowed to eat with the other mothers.
19. One night I heard my son crying and couldn't understand why as all the children were taken into the nursery at night time. I looked outside and down the corridor to see my son was in his crib outside of the nursery door. When I asked why this was, I was told that he had a slight cough, which he did not have. At this point in time all I was told about my Hepatitis C diagnosis was that it was a little virus with nothing to worry about, so seeing my son being treated like this was very upsetting to me.
20. I got my husband to go out and purchase a camcorder, so my son would always know who his mummy was and how much I always loved him. As I had been told I wouldn't see 30. (I can't remember who this was) All this stress, depression and bad health took a toll on my marriage and it deteriorated.

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21. Further, even going to the dentist at Royal Victoria Hospital, I was always left to last and taken to a side room, which was covered from top to bottom in a plastic sheeting and everyone was masked and gowned up. No matter where I went I was treated different and made to feel like an outcast in society.
22. I remarried in 2010 and had another son in 2011 in the Royal Victoria Hospital. Once again I was treated with the same distance I was treated in my first pregnancy. I lost 3 pints of blood, and they wanted to give me a blood transfusion. I asked if my condition was life threatening and they said no so I decided that due to my past history, I wouldn't have the transfusion. The only benefit from the transfusion would be to speed up my recovery time.
23. As previously mentioned I was diagnosed with Von Willebrand disease. In 2012 I was told at the by Dr Orlando McNulty and Dr Gary Benson at the Haematology Department now in Belfast City Hospital that I had "grown out" of the disease and did not need any more treatment.
24. I started doing my own research into the Von Willebrand disease and have found it to be a very dark, scary area. I have found lots of articles with consultants stating that you cannot get rid of the disease as it is inherited, but blood levels may fluctuate and can seem normal, but you can never clear it.
25. After being told this in 2013, I received a phone call from my GP's surgery to tell me that my GP wanted to speak to me as I had tested positive for Hepatitis C. I was confused because I was told that I was clear of everything by the haematology department, I thought that had made me all better?
26. I believe I was discharged from the haematology department as I had refused the blood products after my son's birth. I think they wanted to get me off their books.

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27. Due to the stigma attached to Hepatitis C to this day I am still treated different and shunned on by society for something I did not ask for and something that was no fault of my own. For example, I have many medical issues and currently need a hysterectomy but Dr [GRO-D] is refusing on the grounds that it is too dangerous; he told me that I have a 50/50 chance of survival.
28. I feel like I am still treated, by medical professionals, as if I still have Von Willebrand disease and Hepatitis C even though, doctors told me I was cleared of it.
29. I just feel like an outsider, like I have leprosy and I am an outcast.
30. I feel that my government and the Northern Health Service has let me down, my life would have been so much more fulfilling if I had not been given Hepatitis C. I had a great job as a Book Binder with a great wage and had to give it all up.

Section 6. Treatment/Care/Support

31. During one of my haematology appointments in around 1992, I was asked to be a guinea pig for a new viral drug treatment named Interferon. At this point I asked if I could still have a baby afterwards as I was newly married. They could not give me an answer to my questions so I held off to have a baby first.
32. During this time I started a private case against the Northern Health Service for contracting Hepatitis C through contaminated blood. My case did not go very far as I had to drop it in order to receive money from the Skipton Fund.
33. I can now see how unsupportive my doctors were at that time from letters in my medical records. Additionally, I remember Dr Mayne telling me that I should use the money for something better than litigation, like paying to be hypnotized to have an easy birth. Dr Mayne thought I was wasting my time and money on a case I could never win.

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34. I had a liver biopsy done in 1996 and was told that I now had chronic Hepatitis C. I started injecting the dry Interferon into my own stomach 3 times a week for six months to no avail. At this point I was told I would never see my 30th birthday.
35. In 1998, I started a second trial drug treatment of Interferon injections and Ribavirin Tablets. This involved injecting myself again 3 times a week, and taking six tablets a day for six months.
36. During this time the treatment took a lot out of me and I became a recluse, I lost friends, had no social life, no energy, spent most of my days with my head stuck in the toilet being sick, trembling under a blanket due to extreme cold/fatigue.
37. I had to rely on close family to help me with meals, looking after my child, doing my household duties and helping me get washed and dressed. As a result this was the end of my first marriage. I stopped telling people I had Hepatitis C and told them I had liver problems which led people putting the stigma of me being an alcoholic, even though I did not drink alcohol.
38. At this point I was reprieved and was told that I was PCR Negative and the virus is now in a dormant state, but would always be with me. This was in 2004; I thought I would get my life back and that I could finally make some plans. I think my life would have been very different if I had not received any blood products.

Section 7. Financial Assistance

39. The government offered £20,000.00 to each person accepted to be Hepatitis C due to contaminated blood products, but on accepting this I had to drop my own private case. This payment came from the Skipton fund.
40. In 2008, I started to receive a £250 payment for heating. This is an annual payment for heating I get every December from the Skipton Fund. I found

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out about it through the Haemophilia Magazine who suggested to contact the Skipton Fund. I rang them and they confirmed I was entitled to the heating payment every December. I wouldn't have known about it if I didn't see it in the magazine.

41. I present the following exhibits to accompany my statement:

<u>Exhibit Number</u>	<u>Description</u>
WITN0096002	Letter from Dr E E Mayne to Dr Stewart dated 8 December 1992
WITN0096003	Letter from Dr E E Mayne to Dr Liam Simpson dated 28 June 1994
WITN0096004	Letter from Dr Julia A M Anderson to Dr R Johnston dated 25 June 2003
WITN0096005	Letter from Dr Gary Benson to Dr Morgan dated 3 May 2013

Statement of Truth

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

Signed: GRO-B

Dated 8/3/2019