

# ANONYMOUS

Witness Name: GRO-B  
Statement No.: WITN0198001  
Exhibits: None  
Dated: 17/04/2019

## INFECTED BLOOD INQUIRY

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WRITTEN STATEMENT OF GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13<sup>th</sup> February 2019.

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

### Section 1. Introduction

1. My name is name is GRO-B My date of birth is GRO-B 1968 and my address is known to the Inquiry. I am married to GRO-B and we have two sons aged 17 and 20 years of age. We are blessed to have a lovely home and live in a good neighbourhood.
2. In this statement I intend to speak about my infection with Hepatitis C Virus (hereinafter referred to as 'HCV') from contaminated blood given to me from the use of Factor VIII blood products administered to me after an appendectomy operation. I will go on to describe how this affected my family and me and I will describe the treatment that I received and the impact it had on our lives.

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## Section 2. How Infected

3. I was diagnosed with Haemophilia A as a young child. I grew up living with the challenges presented by haemophilia but I was relatively resilient. I have moderate haemophilia with varying blood accies. I am currently under the care of Dr Gary Benson, Consultant and Director of the Haemophilia Centre based at City Hospital in Belfast in Northern Ireland.
  
4. To the best of my recollection I believe I first started using Factor VIII blood products around the age of ten or eleven. The Factor VIII was administered by The Royal Victoria Hospital in Belfast. At that time I was under the care of the Northern Ireland Haemophilia Centre, which was based at the Royal Victoria Hospital in Belfast. The team there was led and managed by a Consultant by the name of Professor Elizabeth E. Mayne.
  
5. In March – April 1985 my appendix perforated and I attended Tyrone County Hospital in Omagh for an emergency appendectomy operation. Mr Victor Loughlin performed the surgery. I was given Factor VIII blood product after the surgery. Neither I nor any member of my family was given any advice in relation to the risk of being contaminated by blood products prior to my operation. Mr Dominic Pinto took over and oversaw my aftercare two weeks post surgery.
  
6. I believe the Factor VIII product administered to me after my operation would have been transferred from the laboratory in the Royal Victoria Hospital in Belfast to the laboratory in Tyrone County Hospital in Omagh. I imagine either a Junior or Senior House office would have written the prescription for the Factor VIII to be administered to me under the direction of the Consultant in Tyrone County Hospital in accordance with the guidelines from the Belfast Haemophilia team.

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7. I continued to receive Factor VIII after my operation until the method of management changed to syntactical formulate in the form of ReFacto AF. I cannot recollect when the change took place.
8. Following my operation I continued to attend for six monthly check ups at the Haemophilia Centre in the Royal Victoria Hospital. At one such appointment in 1992 I was told that a situation had arisen in England where a patient with haemophilia had received contaminated blood products and been infected with the HIV virus as a result. This information had been communicated to the health authorities. It was therefore recommended that I be tested and attend for blood tests, which I duly did, so that I could be checked for HCV and the HIV virus.
9. My mother contacted the Haemophilia Centre to request my test results. A Junior House officer on grounds of confidentiality refused this request. We were told that the blood results could not be given over the telephone to my mother however she was told there was nothing to worry about and everything would be ok.
10. I attended the Haemophilia Centre at the Royal Victoria Hospital soon after. My wife, then girlfriend, was with me at the time. Professor Mayne said to us that he knew that I had been worried about my blood test results but everything was fine. She said that she was pleased to tell me that my blood tests indicated that I was HIV negative. My biggest concern had been about the HIV virus so to hear this was a great relief.
11. Professor Mayne then went on to say that I had contracted HCV through an infected blood product. I believe that I was infected with HCV from contaminated blood products administered after my appendectomy operation, March – April 1985. There was no mention of when I might have been infected. Since then I have been told that I would have caught the HCV from Factor VIII blood products. Professor Mayne advised me that whilst my blood results indicated that

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I did have HCV as long as I looked after myself this should not affect my life.

12. When I heard the test results from Professor Mayne I was so thankful that I had not been infected with HIV. I felt happy. It was a relatively short conversation and I did not ask any further questions. I thanked Professor Mayne and got up to leave. I recall that GRO-B had remained seated but then got up after me. We left the centre and walked to the bus stop. GRO-B always had an optimistic outlook on life and in our family we fondly used to refer to her as 'GRO-Bpositive' at home. I remember that GRO-B was quiet after this consultation. I knew that she was worried or anxious about something. GRO-B always made sure I attended my medical appointments thereafter.
13. Life went on and GRO-B and I had our first child. I attended for a liver function test (LFP) in 2004, which showed up some abnormalities. I was told that I should make some changes in relation to my diet and given advice in relation to consumption of alcohol. When I reflect back on this appointment I feel that this advice should have been given to me earlier.
14. At this point I began to reflect back on Professor Mayne's advice. In hindsight I now feel that I was not given given adequate information to help me understand and manage the risk of spreading HCV. To the best of my knowledge there was never a conversation in relation to sexual transmission or my risk to others. Looking back now I think I was a fool to have not asked anything. Once I became aware of the impact the HCV was having on my general health I made changes to my lifestyle. I stopped drinking alcohol socially and eliminated fatty foods from my diet. I continued to attend for liver function tests every 3-6 months with the Haemophilia Clinic thereafter.

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## Section 3. Other Infections

15. I cannot conclusively say that I have been infected by any other infection other than HCV. I do however recall receiving a letter from the Haemophilia Centre in Northern Ireland where it was mentioned that there was a possibility that I could have been infected with the human form of mad cow disease, variant creutzfeldt-jakob disease which was referred to as vCJD. I cannot remember when I received that letter and I did not follow it up by going to my GP or seeking any medical advice from the Haemophilia Centre. I put it to the back of my mind and have never taken it any further.

## Section 4. Consent

16. I required Factor VIII blood products post-surgery in 1985. I did consent to their use however I would not consider this to be full and true consent given that I did not have full knowledge of the actual issues and risks of using the same. My consent for treatment was dependent upon my belief that there was a culture of openness and honesty in the treatment I was about to receive. My family and I were ambiguous to the potential danger and risks involved with the sourcing of the blood product. I would say that I certainly did not consent to receive treatment, which could potentially infect me with HIV, HCV, HBV or any other infection.
17. No health care professional ever spoke either to my parents or myself and made us aware of the potential risks involved in the use and administration of Factor VIII.
18. I do not know or believe that I have ever been treated or tested without my knowledge or consent or without being given adequate or full information or for the purposes of research.

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## Section 5. Impact

19. I had always enjoyed a happy go lucky personality. I felt that the world was my oyster and I had met the girl of my dreams. I was young and newly married. When I first learned that I might have received contaminated blood products all this changed. It was the first time in my life that my personality was put to the test. When I received this information I never really spoke much to anyone and I continued to try to be as optimistic as possible. However, as the weeks passed I started to get worried and my family noticed the change in me as I became quiet and withdrawn. For the first time in my life I began to suffer from low mood and depression. I felt and still feel very strongly about the fact that I was never made aware of the infected blood issues.
  
20. I was no stranger to having limitations in place in my life due to the risk of bleeding, immobility and haemorrhagic arthrography. The impact of the HCV did not really reveal itself until October/November 2008 when my liver function started to show significant abnormalities. Clinically I became more symptomatic and this had a physical impact on me. I was becoming increasingly tired and I sweated profusely and felt nauseated.
  
21. When the first course of treatment for HCV became available I volunteered very quickly and I believe I was one of the first people to go for it. The second course of treatment was dependent upon my fibro scan results and my experience surrounding the way in which I was offered the second course of HCV treatment was very different. Dr GRO-D Consultant Gastroenterologist & Hepatologist at the Royal Victoria Hospital in Belfast, offered me the second course of treatment. The management style and the way in which Dr GRO-D spoke to me affected my emotional and mental well being. I am not aware of any other treatments that could have been made available to me at that time.

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22. I commenced my first course of HCV treatment in February 2009. The treatment was administered by Belfast City Hospital, which I felt was a blessing. I was treated with respect and dignity throughout my haemophilia centre. The treatment itself was difficult and debilitating. I suffered severe physical side effects. I was constantly nauseated and I mean constantly. I vomited four to five times a day even though I was taking with antiemetics. After taking my interferon injection I had pyrexia combined with rigours, which would last between thirty six to forty eight hours. On top of this I suffered from mouth ulcers and haemorrhoids.
  
23. My first treatment plan was over 48 weeks. I was required to take 400mg of Ribovarin twice a day and undergo Interferon injections every Monday into my abdomen. I was advised to take Prophylactic anti - depressants for two weeks before my treatment was due to commence and to stay on them for the duration of my treatment. I was told that my personality would change and the anti – depressants would help. I was not keen on taking the anti depressants and did not take them until six weeks had elapsed and I realised that my mood and personality was affected. Around 2009 when I was eight months into my treatment I had to take Neupogen injections for three to four weeks to boost my immune system.
  
24. I also suffered severe mental effects as a result of the HCV treatment. I continued to suffer from low mood and depression. I suffered from neutropenia for the last sixteen weeks, which in turn increased my anxiety. I was particularly worried in case it meant that the HCV treatment plan might be abandoned. I suffered several lengthy episodes of despair, anxiety and an awareness that I was over thinking absolutely every aspect of my day and life. I went through a variety of hopeless, worthless emotions. Consequently I started to take Citalopram, anti depressant medication, starting on a dosage of 20mg before increasing to 40mg.

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25. There was no change in my dental care following my diagnosis of HCV. The Belfast School of Dentistry had always provided all my care so that I was close to the hospital in case anything happened. I did experience more teeth problems after I was infected HCV. My dentist knew of the diagnosis as the Haemophilia Centre had informed him. I did notice that whenever I needed dental treatment the dentist chair would be covered in plastic and the instruments were all covered in plastic. I was taken aback when I saw that the first time and it did bother me a bit to see this but I understood why they had done that. Thereafter, whenever I needed any dental treatment done this was always the practice. I am always offered dental appointments that are at the end of the day. I notice that I am always the last person in the clinic. This can be inconvenient for me as my dentist is far away and it interrupts my day so the rest of the day is not as productive as I would like. I would rather have my appointments in the morning and then be able to plan the rest of my day.

26. We decided not to tell our children about my diagnosis of HCV. They were young at the time about nine years old or so. In 2009 when I started treatment we told them then that daddy had bad blood and that mummy had to inject him. During that first course of treatment I recall my mood was low and I had no motivation. I felt tired and sick and had no energy. I felt that everything was a struggle. My social life became non-existent. GRO-C

GRO-C I went through a very low period and thoughts of ending my life crossed my in mind. My relationship with my children suffered. I felt like I was failing them all the time. I could do nothing with the children during the treatment, not even kick a ball around or go for a walk. I felt bad for them that they were missing out. I timetabled my injections to take them on a Monday so that worst effects would be over by Friday and I would be better by the weekend.



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27. My youngest child is now 17 and he is still unaware of my diagnosis of HCV. My eldest son studied A-level biology and he was able to put two and two together. One day he came home and asked GRO-B if I had cancer or HCV. GRO-B told me about the conversation. The next day it happened that I was going out to Belfast and I discussed it with him then. I explained how I had become infected. He just went quiet. He said he had suspected that something was wrong. He has never asked me anything since and both of my sons do not even know I am submitting this statement to the Inquiry.
28. In terms of stigma, when I used to go for my blood tests at my local GP or Health Centre I always felt that they looked at me differently even though they tried to disguise it.
29. Inevitably the effects of HCV and the treatment plan had an impact on my working life. I was and am employed as a Sales Manager for a Company and I used to work 40-50 hour weeks. I have worked there for 32 years. I told my employer about my diagnosis and they told the employees. In 2009 I did not work for 12 weeks during my treatment and I then went onto light duties 2 days a week. The biggest challenge during my treatment was going into work on a Monday after my injection. That was very hard to do during my treatment. Whilst I was on the course of treatment I decreased my working week to three days. After I started my treatment I was no longer able to maintain a five day week. I still enjoyed the job. People used to joke and say I was a part timer and this would annoy me. I am still doing 2.5 days a week.
30. The change in my ability to work had a severe impact on our finances. My wages were reduced in half. GRO-B was working full time as well. The change in my income affected our family unit. I couldn't buy Christmas presents that I would like to have bought for my sons and it affected our lifestyle such as taking holidays. I now work for a set wage and do not get a bonus as I did before.

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31. I did not have sustained viral load post six month following the course of my treatment. I honestly felt the hospital team were as disappointed as I was. I was fortunate to have the support of a loving family and we continued with the mindset that no treatment was wasted so even though I was not cleared of HCV I did eradicate it for a time and that had to be good for my liver.
32. In 2013 I attended for a fibro optic scan which indicated that my liver function tests were not looking good. I had a long discussion with GRO-B and for no other reason than wanting a longer life with my children I opted to start HCV treatment again.
33. The Hepatic Team in the Royal Victoria Hospital in Belfast administered the plan for my second course of HCV treatment. I cannot reflect positively on the management style of this team and it still disturbs me to this day.
34. I had a consultation with Dr GRO-D Consultant Gastroenterologist & Hepatologist at the Regional Liver Unit, Royal Victoria Hospital Hepatic team in the Royal Victoria Hospital in Belfast. Dr GRO-D spoke about a new triple therapy and although funding was nearly secured the team were unable to discuss this openly due to the vetting procedures of The National Institute for Health and Care Excellence (NICE).
35. Dr GRO-D went on to say that if society in general were aware of the granting of funding then and I quote " people like you, would be banging at the door to acquire a place for treatment'. I am not sure what 'people like you' meant. I had always looked after myself. I had never engaged in in anything experimental in relation to risky social behaviour and I felt that this man did not realise that I had been given this virus by contaminated blood products. The consultation left me feeling very low and worthless.

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36. Notwithstanding this, the team of nursing staff who actually delivered and monitored the second course of treatment were respectful and helpful.
37. The plan for treatment in 2013 was similar to the previous course. I was taking Ribavirin and interferon injections. Six weeks later I was also required to take a third drug, Boceprevir. I was on the treatment for 48 weeks. I suffered from anaemia during the treatment but I did not need the neupogen injections this time.
38. I suffered the same side effects of treatment as in the first course and I would say that my depression and lethargy was probably marginally worse. At one stage my mother cried because she felt guilty due to the inheritance of haemophilia, which led to my reliance on Factor VIII. I reassured her however I am sad to say that on more than one occasion I often felt angry about having haemophilia. I completed the second cycle of treatment in 2013 and this was successful.
39. My life, although now HCV free is upon reflection, not one that it should have been. It has very much been directed by post treatment illness. I feel that the cure is worse than the disease. I suffer from constant pain in all my joints and from the soles of my feet. I am constantly tired and I have difficulty in concentrating. My memory is poor. I have never been able to return to full time employment and have stayed at my reduced hours of twenty-two hours per week. I struggle to sustain even these hours and GRO-B works full time.
40. The second course of treatment was hard to endure and complete. I felt like I would never get to the end of it. I suffered from vomiting, diarrhoea and hair loss during my treatment. I suffered from anxiety and insomnia. The post treatment side effects are hard. I would say it is a case of the cure being worse than the disease. I am under the Pain Clinic in Omagh to help alleviate these problems. I am now left with chronic fatigue, insomnia and joint pain. I take pain relief in the form of

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125mg duragesic patches which release fentanyl into my body. I change these every 3 days. I take Paracetamol and co-codomal for the pain. I also take Abstral tablets for pain relief as and when required. I do not take it during the day as affects driving so I only take it at night.

## Section 6. Treatment/Care/Support

41. The only difficulty or obstacle that I faced in terms of obtaining treatment, care or support is the way in which Dr GRO-D spoke to me before I received my second course of HCV treatment.
42. I don't recollect either myself or <sup>GRO-B</sup> being offered any counselling. Had I been so offered I don't know if I would have taken the offer up. I was never asked if my two boys had ever been tested for HCV nor was I offered testing for them.

## Section 7. Financial Assistance

43. The Skipton Fund was made available to myself via the Haemophilia Centre in 2003 of £20,000, I was advised by medical staff to accept the payment. I accepted the payment eventually. The Stage 1 regular monthly payments commenced in October 2017. I am also in receipt of Personal Independence Payments, which replaced Disability Living Allowance. I found the renewal process with this difficult, invasive and stressful. The application was granted in February 2017.
44. I wonder how these organisations distinguish between patients and how they differentiate between Stage 1 and Stage 2 payments for victims. The payments are better than nothing but they are no comparison on my lost earnings due to my inability to work full time. They simply do not equate to the same. I don't know how we would have survived without my wife's wages.

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Section 8. Other Issues

45. I confirm I have never been involved in any earlier litigation, inquiries, investigations or campaigning concerning the use of infected blood or blood products.
46. I still struggle to and try to maintain a positive mental health outlook to this day. However I am very grateful to be alive with a healthy liver and hopefully my boys will have their daddy for longer.
47. I often think about the time in my life that has shaped the way I am today. The emotions of anger, hurt, dishonesty and shame, yes shame. I have always felt dirty, identified as the 'dirty case', kept to the last on every treatment list possible. Yet you reflect also trying to balance the fact that you are alive and have been blessed with a fabulous family that love you with all their heart. I have tried for years to keep positive but have failed miserably and still I remain embarrassed to admit but this has taken a massive emotional toll on my life. I contemplate daily and I mean daily, the 'what ifs' in my life.

Statement of Truth

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

GRO-B

Signed \_\_\_\_\_

Dated 17/04/2019