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Witness Name: GRO-B

Statement No.: WITN0367001

Dated: 19.08 2019

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 11 January 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

- 1.1 My name is GRO-B born GRO-B I am a mother and I reside in the North-West of England. My full address is known to the Inquiry.
- 1.2 I live with my youngest son who is also my registered carer. I had four children, three sons and a daughter who were born in 1979, 1988, 1995 and 1997 respectively. My eldest son passed away in GRO-B 2018.
- 1.3 I intend to speak about my experience contracting the Hepatitis C virus ('HCV') following a blood transfusion. In particular, the nature of how I found out about the infection in 2015, my illness, how the illness affected me, the treatment I received and the impact it has had on my life and the lives of my family.
- 1.4 I confirm that I have chosen not to be legally represented in regards to providing evidence to the Inquiry.

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- 1.5 The Inquiry investigator has explained the anonymity process to me. I have elected to have my name and personal information redacted due to the possible stigma that myself or my family may face if this was widely known. I hope that my story will give others confidence to tell their story and to provide them with solace to know they are not alone.

Section 2. How Infected

Blood Transfusion

- 2.1 In July 1985 I was 27 years old and I was in a very violent relationship. I knew I needed to leave my partner of eight years, because he had become very violent towards me because he was suffering from paranoid schizophrenia.
- 2.2 After many violent episodes in June 1985, he attacked me in front of our six-year-old son. I was assaulted so badly that I had a broken nose, it felt like it had been moved to my left ear. Following the assault, I left the house with my son and was found in a public phone box trying to ring for an ambulance.
- 2.3 I was admitted to the Crumpstall Hospital now known as the North Manchester General Hospital, where corrective surgery was performed on my nose. I did not receive any blood transfusions or blood products during this hospital admission. I had no family or support from services.
- 2.4 My partner was placed in prison for two weeks, and upon his release he returned to our home. I had no choice but to leave. This meant I was homeless with my son for three months whilst waiting for council accommodation. The only money I had was child benefit, as my partner had told the Department of Social Security that I was still in a relationship with him and living with him.
- 2.5 Whilst I was homeless, I found out I was pregnant. I could not cope with being homeless with no money and a child, as well as being pregnant. It

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was as a result of all of these circumstances I decided I needed to have a termination. I was booked into the Manchester Northern Hospital for the operation in September 1985.

- 2.6 I was advised and expected to be kept in hospital overnight after the operation. The night following the operation, I awoke in the middle of the night suffering from pain and heavy bleeding. I believe I was passing baby body parts. They believe that I could have been pregnant with twins but I am not sure.
- 2.7 The heavy bleeding meant the doctors had to perform an emergency procedure on me. The amount of blood I lost required me to have a blood transfusion. Due to complications from the procedure and the amount of blood I had lost I was kept in the hospital for four days.
- 2.8 I do not believe there was any discussion prior to the operation about the risk that came with blood transfusions; but I do acknowledge that this was an emergency situation and that the blood transfusion I received saved my life.
- 2.9 I am aware that HCV can be transmitted by blood and some of the most common ways of infection are tattoos, intravenous drug use and blood transfusions.
- 2.10 I have only had one blood transfusion. I did not have a transfusion when I was admitted and operated on following the assault the month prior.
- 2.11 I believe that I was infected with HCV during the blood transfusion following the termination, this is the only occasion I have been given blood products. I do not like or have any tattoos and have never taken intravenous drugs.

Hepatitis C

2.12 I have suffered with bad health throughout my life, and in September 2015, I kept passing out. I went to my General Practitioner ("GP") to find out why I kept passing out and what was wrong with me.

2.13 My GP sent me for a blood test which showed that I had a raised liver count. I believe that I had another blood test testing for HCV, which came back positive.

2.14 I was very upset, shocked and angry about the diagnosis. I had always associated the infection with IV drug users and tattoos. I remember asking my doctor how I had become infected, when I was not a drug user and had no tattoos?

2.15 I remember the doctor told me that you can get HCV through sex. I felt very angry at the doctor's suggestion that I was infected because of sexual promiscuity.

2.16 My GP originally gave me the option to be referred to either **GRO-B** **GRO-B** or **GRO-B** for my first consultation. Due to the stigma associated with the disease and as I thought I was less likely to see somebody I knew at **GRO-B** I chose this hospital even though **GRO-B** was closer to my home.

2.17 In September 2015, I had my first consultation at **GRO-B** I remember walking in, and the doctor looking down at my hands, it felt like he was checking me over to see if I was an IV drug user. I felt like I was being stigmatised.

2.18 Even though I had selected to attend **GRO-B** I was advised that my treatment could start sooner if I went to **GRO-B**

2.19 Towards the end of April 2016 and at the beginning of May 2016, I met with the Hepatology Nurse Specialist, who was extremely supportive throughout my treatment, and said I could contact her at any time.

Information

2.20 I do not think that I have been given adequate information, from those treating me, about the disease. I was given information by my Hepatology Nurse Specialist about the treatment involved, and the side effects associated with the treatment, but I was not been given information about preventing the spread of the infection or any risks associated with the infection itself.

2.21 I would like to have known more about how the treatment and how the disease affects your brain.

2.22 I have had to educate myself about HCV. It would have been helpful to have been given information about preventing the spread of the disease. I feel very lucky it did not affect my children or anybody else I know. It would be quite easy to pass on without knowing, having had the infection for 30 years undetected.

Section 3. Other Infections

3.1 I do not think that I have received any other infections other than HCV as a result of being given a blood transfusion in 1985.

3.2 I assumed that I would have been tested for HIV within the last 10 years as part of routine screening when I had other blood taken but I do not know.

3.3 I believe my extreme exhaustion, Vitiligo, paralysed nerve, emphysema and general poor health for the last 30 years is a consequence of having been infected with HCV. It has silently been damaging my body all this time.

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- 3.4 I am aware that HCV can cause Cryoglobulinemia, Raynaud's Disease. Although I have not been diagnosed with this condition, I do suffer with all of these symptoms, I worry I also have these conditions.

Section 4. Consent

- 4.1 I do not think my blood has been tested without my knowledge or consent after receiving HCV treatment.
- 4.2 I have taken part in experimental procedures concerning my lungs but I have consented to these operations.

Section 5. Impact

Physical and Mental Impact of HCV

- 5.1 I am sixty-one years old and have had HCV for nearly half of my life without knowing about it. I am now disabled and have many terrible illnesses that I have to cope with all the time. I have tried to discern what may have been caused by the HCV infection, but I do not know.
- 5.2 When I was 18 years old in 1976 I worked as a student Psychiatric Nurse at GRO-B Hospital and then at the GRO-B Hospital until 1978 when I left employment to have my first son.
- 5.3 On Christmas Day in 1981 I was in a bad car crash and required hospitalisation. I did not receive any blood transfusions during this admission.
- 5.4 While I did not show any obvious signs of having HCV, since finding out I have had this infection since 1985, it now explains why I was constantly tired and why I was suffering from 'brain fog'.
- 5.5 On reflection the tiredness and slow recovery I had following my operation in 1985, could be attributed to having the HCV infection in my system. It

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took me over three months to recover from the operation. I had always attributed this to my domestic situation at the time, the blood loss I suffered whilst raising a young child.

- 5.6 In [GRO-B] 1988 I had my second son. I had always thought that the problems I suffered during my pregnancies were as a result of my existing health conditions following the car crash. Where in fact it could have been because of the HCV.
- 5.7 As a consequence of the HCV I never had the vitality that I should have had as a young woman. There always felt like there was a cloud over me, with weight on my legs and arms. I thought I was traumatised by what had happened to me in my life. In hindsight, this was all as a result of HCV. I lost all of my inspiration and motivation.
- 5.8 Due to my extreme exhaustion I used to pay people to take my children to the park to play. I was too tired to take them myself. At the time I lived in a hilly area, and attributed a lot of my health issues to my bad asthma. Now that I know about HCV, it also provides an explanation for my fatigue.
- 5.9 This fatigue has robbed me of so much pleasure with my children whilst they were growing up. My everyday life was a struggle and was more difficult than it should have been.
- 5.10 I developed Vitiligo around 2010 which was diagnosed in 2011. I remember that when I met my Hepatology Nurse Specialist for the first time she told me I was transparent, which was true. I have lost most of the melanin in my skin on my face and my arms and body are extremely patchy. I cannot absorb vitamin D from sunlight anymore and unable to sunbathe and visit a hot country anymore. My Hepatology Nurse Specialist at [GRO-B] told me that Vitiligo was a consequence of having HCV.

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- 5.11 I have noticed that I have a problem with my fingernails dinting and splitting, and have lost one fingernail on my left hand. I have been told that this may be as a consequence of having vitiligo.
- 5.12 I am aware that HCV can cause Cryoglobulinemia, which causes difficulty breathing, fatigue, joint and muscle pain, and Raynaud's Disease. Although I have not been diagnosed with this condition, I do suffer with all of these symptoms.
- 5.13 Even though I was cured in August 2016 of HCV, I still suffer from fatigue and depression, there is not a day goes by that I do not think about what happened to me in 1985. I feel like I lost my life's vitality at that time.
- 5.14 Mentally it was challenging when I was first diagnosed with HCV. It was confronting to have to address my own misconceptions about those that have HCV. I was suddenly someone with HCV but I wasn't who I thought got HCV.
- 5.15 I also lose power and strength in my knees quite often and fall because of it. I also drop things without warning. I am now unable to cook, which is something I used to love doing.
- 5.16 The physical and mental impact of HCV have totally shaped all aspects of my life, it stubbed the potential I had and dulled the life I can now lead.

Treatment

- 5.17 I remember that the nurse specialist told me that the treatment I was going to receive was very expensive and that I was lucky to be having it. I thought thank God there's something you can do about the infection.
- 5.18 It took six months from diagnosis, until I began the treatment of Interferon and Ribavirin in May 2016. During this time, I felt like I was dying. I felt dirty and could not share my infected status with anyone. I felt that I was being seen as an intravenous drug user or sexually promiscuous.

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- 5.19 The Hepatology Nurse Specialist told me that the treatment would make me very ill and it would feel like I had the flu permanently. I was told that the treatment was worse than some treatments for cancer, that my hair would fall out and become very thin and that I would feel suicidal.
- 5.20 The treatment required me to take two tablets every morning and a weekly injection which I gave to myself. I remember doing my first injection in front of the Hepatology Nurse Specialist to make sure that I was doing it correctly.
- 5.21 The course of treatment lasted four months and every two weeks I went to the hospital for a blood test. I think this was to check how effectively the treatment was working. I recall that Hepatology Nurse Specialist said that I was responding well to the treatment and that I would be kept on the medication.
- 5.22 The treatment was gruelling. I felt like a 'wisp of smoke'. I would lie on the sofa all day and would only be able to move to go to the toilet. The fatigue I had was 'off the scale.' I had absolutely no energy, my whole body ached. The only way I can describe it to someone would be is to imagine the flu, then amplify it by 1000%.
- 5.23 I remember we had a kitten at the time and even the kitten laying on my lap or hip was too much weight on me, it caused too much pain.
- 5.24 I had never been a depressive person, but by the end of the treatment I was suicidal, I thought I would rather die than continue with the treatment. I wanted to end it all. People have committed suicide as a result of the treatment given.
- 5.25 My depressive feelings impacted my relationship with my oldest son, who was caring for me at the time. He became depressed himself as a result of hearing his mother talk about death.
- 5.26 I have spoken to others who have had the Interferon Treatment and I don't believe I am alone in how horrible it is on your physical and mental health.

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Interferon treatment is toxic. It is completely detrimental on the mental health of the person taking it. It is completely destructive. How the treatment affects your brain is awful. I think that infected people should only be given the new, non-Interferon treatment protocol.

5.27 The Hepatology Nurse Specialist told me about all of the side effects, so it was no surprise. However, I was surprised by the severity of tiredness and not being able to put one foot in front of the other.

5.28 Fortunately, the treatment worked and I was cured of HCV in August 2016 and I am grateful for that.

My Life

5.29 I left Manchester and moved to GRO-B in 1990. I wanted to be as far away from my past life as my circumstances could take me. I had put what had happened to me in Manchester as far away from my mind as possible.

5.30 In 1992 I had obtained a place at GRO-B to study GRO-B starting in September of the same year. I did not go. I did not have the energy to travel, study and look after my two boys. I now know that I was suffering from fatigue caused by HCV.

5.31 The lack of energy I experienced was affecting every part of my life and I developed anxiety. I never asked for help with my anxiety from my doctor. I had been taking Dosulepin to treat sciatica, and was worried that I might lose my youngest children if I told the Doctor I was struggling with anxiety.

5.32 In GRO-B 1995 I had another child, my daughter, and I was thrilled. After six days of being home I became very ill. I was diagnosed with a paralysed nerve running from my brain down through my shoulder into my right arm. I became more and more anxious and even more so when I was told there was nothing that could be done about it.

5.33 The circumstances of my HCV infection are very difficult for me to cope with. I kept the past at bay until I was diagnosed with HCV, it has all come

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vividly back to me. I had to relive being in a violent relationship. Emotionally I felt like I was back in 1985, with the struggle of leaving an abusive relationship, being homeless trying to find somewhere to live with my six-year-old son, and moving into a flat with no furniture and having to sleep on the floor. I had to start again from nowhere and I had to do it all myself.

- 5.34 It is embarrassing having to tick the box about my HCV infection, people assume the worst, they do not know that I was not an IV drug user or prostitute.
- 5.35 I found out that I was infected over 30 years after contracting HCV, and before the birth of my three youngest children. They were tested for the virus, which was negative for all three of them. My eldest son however, was born before I had contracted the virus, and as such I was told by doctors that he did not need to be tested. Given that I had the virus for 30 years without knowing, and its transmissibility, I do not know whether my eldest son was infected from HCV. The impact of my illness, however definitely affected him and our relationship.
- 5.36 I did not concentrate on having a social life, my life was focussed on being a parent, and that was my priority. All my energy was taken raising my children. My main ambition was to be with my children.
- 5.37 Having HCV has also impacted on other familial relationships, specifically with my mum and sister. I come from a family of high achievers and have never felt able to share the extent and nature of my illnesses with my mother and sister. They do not know my tiredness and illnesses which have plagued my life are from the HCV infection. HCV sucked the vitality and zest for life from me.
- 5.38 My wider family consider me to be a 'bum and lazy' who could never get my life together. I am the black sheep of the family.

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5.39 I have not told most of my wider family about the HCV. I believe they have misinformed beliefs about it and I don't have the energy for it.

5.40 I did not have the energy to pick up a career. One of my biggest regrets is not being able to afford my own home, continually living in rented accommodation, you have no security in the place you live. This has had a significant impact on me.

5.41 HCV has had a substantial and long-term impact on my health and has impacted on the ability for me to carry out everyday activities.

Section 6. Treatment/Care/Support

6.1 I do not believe I have faced obstacles in obtaining treatment once I was diagnosed with HCV. You do have to tick that box to say that you have had HCV, and there is no opportunity to say how you got it.

6.2 I was not offered any counselling or psychological support at the time of receiving the blood transfusion, and have not received any at the time of being diagnosed with HCV or throughout the treatment of the virus. My Hepatology Nurse Specialist was very good throughout both prior to and during the treatment. She provided me with support, and gave me her telephone number which I could call her on at any time.

6.3 I have discussed with the Inquiry investigator the existence for the counselling and psychological support service the British Red Cross is running in collaboration with the Inquiry. I have been provided their contact information and will consider using it.

Section 7. Financial Assistance

7.1 I was informed by my Hepatology Nurse Specialist about the Skipton Fund, after she had read my medical history and found out I was infected as a result of a blood transfusion in 1985.

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- 7.2 I remember that the process for applying for the fund was relatively straight forward. I had to fill in a form and send a copy of my medical records to the Skipton Fund. It was a bit challenging getting my medical records from my doctor, but the process of applying was very easy and the Skipton Fund was brilliant.
- 7.3 Initially, I received a one-off lump sum of £20,000 in 2016. This enabled to pay off all of my debts. I now receive financial support from the England Infected Blood Support Scheme ("EIBSS"). Since April 2018, I now receive payments of £4,500 every three months under the Special Category Mechanism ("SCM"). I also receive a winter fuel allowance payment of £519.
- 7.4 Prior to the SCM payments my financial goals were to make sure that my bills were paid and that I had enough money for groceries. I did not have enough money to pay for my own son's funeral. Since receiving the SCM payments, the financial pressure has been taken off of me. I am able to afford things that I previously went without.
- 7.5 I am very grateful for the amounts I received and continue to receive, but the virus has ultimately impacted on my ability to study and to pursue a career. I would have had a good job and career. I believe I could have really made something of my life.
- 7.6 HCV has had an unbelievably big impact on me not being able to work. I have not been able to purchase a home, which annoys me, and I could have given my children the opportunities to do things that I have been unable to do. One of my biggest regrets is that I cannot buy my own house. I have not been able to provide them with the security of being in our own home, a cloud of 'would we have to move?' lingered while they grew up.
- 7.7 I now receive the Personal Independence Payment benefit and other benefits due to my inability to work. I am reliant on the payments I receive

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from the EBISS to make up the shortfall from PIP payments and the cost of living. I would struggle financially if these were to stop.

- 7.8 I understand that in the Republic of Ireland a one of lump sum payment of £250,000 is made. The payments made should be standard across the United Kingdom and not determined according to your geographical location.

Section 8. Other Issues

- 8.1 My main grievance is that it has taken 30 years for me to be diagnosed with HCV. I have received numerous treatments from medical professionals, and have had three children between the date of infection and the date of diagnosis. There were at least three opportunities were to pick the virus up and treat me earlier, so why was it never tested for?
- 8.2 Aids and HIV were big in the media in the 1980s and 1990s and received lots of celebrity attention. Surely blood is tested for HIV and Aids, so why not HCV? Why was I not tested back when these other diseases were at the forefront of the media? There needs to be a greater awareness of HCV in society and in the medical profession.
- 8.3 I think that Public Health England should be completing a look back exercise screening individuals who may potentially be infected.
- 8.4 I believe it was covered up and is still being covered up, that is why there is no follow up going on. There should be some sort of follow up with recipients of blood. They knew that bought blood was contaminated and they carried on doing it.
- 8.5 It should have never have happened and should never have taken me over 30 years to be diagnosed. 30 years of living with extreme fatigue and brain fog.

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8.6 It is a political cover-up; the Government must have known. I sometimes think they had hoped everyone had died before it became public knowledge. There should be a meaningful apology for this disaster. People's lives are more important than the Government's reputation. One of the main things that hope comes from this Inquiry, is that something like this never happens again.

Statement of Truth

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

Signed

GRO-B

Dated

19:08:2019