

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2147001

Exhibits: WITN2147002- 015

Dated: 10<sup>th</sup> November 2020

## INFECTED BLOOD INQUIRY

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FIRST 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 5 November 2018.

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

### Section 1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B**  
**GRO-B** My name when I was younger was **GRO-B** I am not currently working due to ill health. I am divorced and I have two daughters aged **GRO-B** I intend to speak about my infection with hepatitis C. I will speak in particular about the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me and my family.

**Section 2. How Infected**

2. I was diagnosed with acute lymphoblastic leukaemia on 5 December 1980, when I was a year and ten months old. I received platelets on 6 December 1980 and over the course of 1983 and 1984. These were part of my treatment for cancer. As a result of the treatment, I was infected with hepatitis C. My mum remembers that I had a transfusion within twenty four hours of being admitted to **GRO-B** I was given chemotherapy straightaway and then radiotherapy when I was two years old. I exhibit a summary of the relevant medical history as **WITN2147002**.
3. When I was younger, I was treated at **GRO-B** in Glasgow. I only have a few memories of this. My parents have shown me pictures and have explained to me about my health over the years. I visited Ruchill Hospital and **GRO-B** It was not until I was a teenager that I went to Glasgow Royal Infirmary.
4. There were a number of doctors I was treated by at **GRO-B** over the course of my time as a child and then later on. I was treated by Dr Willoughby, Dr Pettigrew, Dr Kelt, Dr Hann and Dr McCulloch. I was told by my parents that these doctors treated me. I remember being treated by Dr Brenda Gibson, Dr Donaldson, Dr Watson, and Dr Murphy. These doctors were at **GRO-B** and Glasgow Royal Infirmary. I remember being treated by Dr Morris and Sister Neilson at Glasgow Royal Infirmary. I do not believe my parents were ever told of any risks when I was given blood products.
5. I recall being told a long time ago that there was a letter from Brenda Gibson which said that I presumably contracted hepatitis C from blood products. I have been unable to locate this letter in my medical records though and there is a lack of early records from **GRO-B** in my notes.

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6. In 1991 [GRO-B] I can remember having regular journeys to two hospitals in Glasgow. [GRO-B] [GRO-B] so this was a lot of disruption to normal family life. I have vague memories of waiting in a corridor in [GRO-B] while my parents were talking to the doctors. I do not remember exactly when I was told by my parents I was infected but it was in 1994. I know in a letter from 1995 it was mentioned that my liver function had been rising for a few years. In my notes there are blood results that show my liver levels AST and ALT had been increasing.
7. When I went to the clinic run by Dr Watson or Dr Franklin every six months I would have my growth and hormones checked and I would get ultrasounds. I always questioned the purpose of this. I never really knew why and they never said why. Reviewing my records after 1995, I can see that they have been monitoring my liver with these ultrasounds. I believe they also checked my siblings. [GRO-B] I thought this was a cover-up. There are a couple of medical trials I was part of in relation to my leukemia. There were trials in Edinburgh and a trial in Oxford Street with children with leukemia. I recall that the Oxford trial I was part of lost some samples at one stage. I am unable to locate details about the trials in my medical records however. I exhibit potential batch numbers that I have uncovered and would like it clarified are these the batches that infected me? If not, when was I infected? I exhibit this as **WITN2147003**.
8. I do not really know what was specifically said to my parents about hepatitis C. Doctors did not include me in discussions initially. I feel that as a family we were given very little information. I exhibit a letter as **WITN2147004** dated the 12<sup>th</sup> December 1994 from Dr Gibson to my GP. This is not my recollection of how the consultation went. My dad researched information for us and shared what he discovered with a doctor at one point. Looking back surely it should have been the other way round.

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9. It transpired that I was serotype 4. It is my understanding that this is quite rare in the UK population. I exhibit a laboratory result as **WITN2147005**.
10. There was just not enough information given to my parents. I believe they were told at the time that hepatitis C could affect what jobs I could do. I remember being told that it could affect me going into nursing as I had wanted to do this since I was very young.
11. The risk of infecting others was discussed with the doctors. I recall them mentioning to me at one point that I should not share toothbrushes. My mum said she tried to shield me from a lot of what was said though. For example I remember them saying to be careful when I had a cut. I have a recollection that I received a letter at one point relating to sexual activity but I cannot recall much more about this. I believe that any conversations about cross-infection routes were had between the doctors and my parents.
12. I do believe I should have been told earlier about my infection but I do not know what they would have done treatment-wise because of my young age. There was a mention of my raised AST/ALT levels which as far as I know, were increasing over time. This was mentioned in 1994. Over the years chloride and other levels were noted as being abnormal in my blood. I believe when AST levels overtake ALT levels there is suspicion that a patient has cirrhosis of the liver. To my knowledge I don't have cirrhosis, but I do have some scarring and fibrosis which was found in my liver biopsy in 1995.
13. I am aware that Dr Gibson gave my parents some information. I think the main issue with how it was being communicated was that I was excluded from a lot of the discussions so my mum would be better placed to answer what information was given. I got the impression that the doctors were afraid of saying too much or not knowing what they

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were talking about. I remember one letter that said that they knew a lot of haemophiliacs were infected with HIV and hepatitis C.

### **Section 3. Other Infections**

14. I was infected only with hepatitis C. My mum recalls a period of us waiting to see if I had been infected with anything else. This was very distressing for everyone.

### **Section 4. Consent**

15. In terms of consent I would say that I was tested without my knowledge or consent as I was a child for much of my time having my blood taken. I remember one letter saying they were checking on my liver and doing blood tests. When I was involved in the trials in Edinburgh which I describe above, before the Oxford trials I got the impression that they may have been testing me with samples given for both of these trials.

### **Section 5. Impact**

16. In terms of the symptoms of hepatitis C, I noticed that prior to my diagnosis and now, I was always experiencing sore legs and joints. My family and I would always go walking on the beach GRO-B and I would notice that I could be very sore. I was not as mobile as my sister and at the time it was hard to tell why.
17. I suffered from migraines and headaches prior to my diagnosis. From what I know now, I would like to know what the impact of having hepatitis C is, on the brain. I feel that it has had an effect on me and doctors have only vaguely said that an awful lot has happened to my body as if that's an explanation for it.

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18. My symptoms got worse when I was about the age of thirteen in 1992. I think we probably initially thought it was just down to my age. I remember being told I might never have children. I think everything that was going on with my body muddled what the source of those symptoms was. I was an unhappy and shy teenager and had no self-confidence due to my ill health.
19. There was always something going on with my health. I remember having headaches or migraines which did not improve after taking various migraine medications. It was only in 2015 after I had a blackout in the car that it was thought I had epilepsy. I have not driven since. My life has completely changed since this happened. I stay in the house most days and I have become a bit of a recluse. This also brings back memories of being a recluse when I was younger.
20. I was affected by brain fog and that did affect my concentration. I was sitting exams around the time that my symptoms started. I do believe that my condition did have an impact on my school performance. I missed a lot of classes through illness, but I was fortunate in that I had a good guidance teacher. I was able to finish fifth year at school with Highers
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21. Regarding my epilepsy, after I blacked out, I went to see Dr Taylor, who is a neurologist. From the results of an MRI scan Dr Taylor said that it looked as if I was fifteen years older than what I was or an alcoholic. From what I have read, many people have been in my situation when they unknowingly had hepatitis C and believed it to be epilepsy. I now know that I have complex partial seizures and non-epileptic seizures. I question how the liver has affected and possibly damaged my brain. I have read about hepatic encephalopathy. However I am aware that I had mild liver disease and not cirrhosis but I have not yet had this clarified. I have a lot of unanswered questions.

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22. In 2017/18 I had a few lesions removed from my scalp which were basal cell skin cancer (non-melanoma). When I visited GRO-B Glasgow, in 2018 I was told it was mostly to do with treatment I had recieved when I was younger. I do remember burning a lot in the sun when I was younger. I would have painful ulcers and my skin has always been sensitive. This is ongoing and I am treated for this through dermatology.
23. I have had general aches and pains throughout my life. I still suffer from tiredness, which is sometimes really more fatigue than tiredness. I also suffer from chronic depression. I do believe that these are mainly related to the hepatitis C.
24. I started interferon treatment in 1995. I exhibit a letter from Glasgow Royal Infirmary to my GP describing my treatment 6 months into it as **WITN2147006**. I recall a time when my dad went to collect my medication from Boots and he was furious to find that they had not stored the Interferon correctly. It had not been stored in a fridge and it took another few weeks for more to come in. I exhibit one of my medical records which lists the side effects I was experiencing as **WITN2147007**. I lost weight and was borderline anorexic. My thyroid was affected and I had no appetite. I suffered from alopecia and lost chunks of my hair.
25. I recall Dr Austin referred me to counselling. It was put in a report that I was exaggerating the effects of interferon, they said I was overreacting and I would need emotional support. I didn't appreciate this.
26. Eventually counselling of some sort was found and after 6 months I was asked if I wanted to do art therapy. I went to art therapy and this was not found to be of any help, because it was recorded that all I wanted

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to do was talk and I did not focus on the art. I can remember feeling very confused and alone.

27. Despite this, the treatment was initially successful and I became PCR negative for 2 months. Unfortunately I then became positive again and I continued on the interferon for nearly 18 months. I injected this myself. It was assessed that I would likely become PCR positive again though and as such, it was agreed in April 1997 that I would commence combination treatment. I exhibit **WITN2147008**. There was a delay in commencing this though because of financial considerations. When the financial matters were approved, I was, in October 1997, advised that this treatment was the best course of action given the “advanced” nature of my liver disease. I exhibit a letter to my GP from Mr Morris discussing this as **WITN2147009**.
28. On the day I was to commence this combination treatment in November 1997, to everyone’s surprise and after a lot of worrying information about my liver, it was discovered that I was PCR negative. I exhibit **WITN2147010**. I therefore did not commence the combination treatment and was monitored instead. This left me with a number of worries about my health. The treatment is very difficult and at a young age I had prepared myself to commence another round of this treatment after all the warnings about my liver, to be told literally on the day, that it wasn’t necessary. It left my family and me with worries that were then repeatedly dismissed. I exhibit **WITN2147011** and **WITN2147012** where it was reiterated to me that I was considered cured of hepatitis C. I also exhibit **WITN2147013** describing my anxieties about hepatitis C in 2005.
29. Years later in 2004 when I applied to the Skipton Fund I received a letter from John Murphy advising me that the results of the biopsy in 1997 did not suggest I had cirrhosis. Given the language used in previous letters and consultations I have not felt reassured and it has



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been extremely confusing and isolating. I exhibit this letter as **WITN2147014**.

30. My depression started from the time when I was diagnosed with hepatitis C. I did not socialise much or do things that other teenagers would do. I did not have a lot of friends when I was younger

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31. My depressive symptoms got worse while I was on treatment and I had no motivation to do anything. I also had brain fog and my legs were very sore and sensitive. I just wanted to stay in my bedroom and cry. My family had to push and encourage me to keep going.

32. To our knowledge as a family we weren't aware of other treatments available.

33. I suffered from symptoms of Raynaud's Syndrome which causes issues with the nerves in fingers and toes. There's also mention of rheumatoid arthritis in my notes. I feel like I have to go through the story every time that I am with a new doctor as they only see the snapshot from my medical records.

34. 

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 I had difficulties with the dental practice when I returned. My sister and daughters were with me for an appointment and the dentist asked to have a word. My sister left the room with my daughters. The dentist and dental nurse were present and the dentist said that if they were going to treat me, that I would have to be the last appointment the day. They said they would have to deep clean the dental surgery after I had been. I wish I had said something at the time. They made me feel like a leper. I reported her to the NHS helpline but nothing came of it. It was stressful trying to get a new

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dentist. Again I had to discuss personal health issues which was difficult when I did eventually find a new dentist. This was upsetting, humiliating and exhausting. I was a young single mum and I had to try and be strong for my daughters. My family were very supportive especially my dad.

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36. My condition did have an effect socially, as I was a young girl when I experienced a lot of the symptoms of hepatitis C and its treatment. I had very few friends. I had a number of hang-ups about my self-image growing up. I felt odd and different and I was not confident. I was socially withdrawn. It would take a lot of effort to get me to go out. I had huge hang-ups about my hair due to alopecia. All I could see when I looked in the mirror was me looking like a freak. The alopecia started during treatment, and my hair has been thin ever since. I am even affected socially now as I have had skin cancer spots removed from my scalp. I have regular ongoing checks. Epilepsy has also played a part in it. I do not go out to many places. I went on holiday in 2018 to Spain and I did not go out much. I feel vulnerable after all the health problems I have had and what I am still going through.

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37. I can't take my daughters places now because of the fact that I can't drive and I do not feel well. I feel I would be a stronger mother if I hadn't been though the traumatic events of my formative years.
38. In my adult years I have never been a socialiser, and also not a drinker. I would often be the taxi driver on family nights out. Now, as I have to be driven a lot, I can be a "backseat" driver now which frustrates me.
39. In 2016/17, I started to have seizures where I wouldn't be able to stop. I had to go to Accident & Emergency a few times. Doctor Taylor thought that these were non-epileptic and sometimes I would have to write down what I wanted to say because I was unable to talk or move. Medical professionals were not empathetic and understanding. My daughters witnessed a lot of this. Too much information was discussed in front of them in situations like this.
40. I do not believe that my condition has had an educational impact on my daughters. I feel I was pressurised into telling my daughters about my hepatitis C as this was being discussed in front of them during appointments. I was worried about what they would think of me. I also worried about them discussing it with their friends and not necessarily saying why or how I contracted hepatitis C, and then other people would make assumptions based on that. People judge and people are cruel.
41. With regards to my epilepsy I went to GRO-B last summer. I was supposed to be there for four weeks and I went in for one week and then I was home for a week and then back for another two weeks. This was to assess what type of epilepsy I had and work out a treatment plan. They established that I do have epilepsy and the treatment is working but they feel as if this is not helping my mental health. I have seen a psychiatrist called Dr Gordon twice to help with my non-epileptic seizures. Since seeing Dr Gordon my anti-depressants have been

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increased. I'm on something called Sertraline. My neurologist wanted me to see someone else but there is a two year waiting list. I am in the process of changing from Kepra to Tegretol for epilepsy. I am on Amitriptyline for my pain/nerve pain. I suffer from pain from my skin lesions. I take vitamin D because my levels are low. I take Paracetamol regularly and Dihydrocodeine occasionally.

42. I have a list of health issues which have had a huge impact on my ability to work. I wanted to be a nurse and after my degree I did occupational health. I was put off from nursing by my diagnosis of hepatitis C. Dr Gibson said that I could not be a nurse if I had hepatitis C. I did feel at a point that I was directionless and it did stifle my ambition. It has been important to me to stay at home around my support network of close family and friends.

43. I have tended to stay at home or near to home through my life, so I have not had the full independence that I wanted. I may have travelled further afield when I was looking at my education and career prospects had it not been for my health.

44. I felt strong enough to move away from home in the year 2000. GRO-B  
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GRO-B I remember having to explain yet again about my health history when I registered with a new GP practice. I came home most weekends as I was homesick. GRO-B  
GRO-B This was a surprise as due to my earlier health issues I did not believe I would be able to get pregnant.

45. In relation to the epilepsy, I do believe my health has stifled my ambition to progress in my career. My previous role was a GRO-B  
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**GRO-B** I am very unhappy that my life has changed.

46. In terms of financial impact, I have no life insurance and have never really thought about it. I don't have a mortgage and I am unsure if I could get one. I am a private tenant where we are currently living. If my health had been better I would have expected to have a mortgage by now and a completely different life.

47. My health also had a huge impact on my family life. **GRO-B**  
**GRO-B** My parents frequently travelled with me to hospital in Glasgow. I believe it was a huge frustration for my dad that he could not get answers about my health. I sometimes felt that my dad was controlling over a lot of things, and I think he thought he knew best all the time. I feel that our lives were ruined by what happened. I think part of this was due to him not having any control over what happened and that's why he had such a bad reaction to it. **GRO-B**  
**GRO-B**

48. I felt like my parents got angry at me when I was a teenager. I felt like I was a problem child and if something happened it would be to me. I felt like my dad felt he had to be more protective of me because of my health. My brother and sister frequently had their lives disrupted. I now know the reason why I did not feel well as a teenager and my family have all been very supportive and understanding about my health issues.

## Section 6. Treatment/Care/Support

49. The support that has been offered to me has been completely inadequate. I do believe I would have benefited had they been more proactive with offering treatment. I feel that it would have been helpful

if I'd known the effects of treatment rather than told I was exaggerating by doctors. I feel that knowing more about my condition could have helped with the depression I went on to suffer. I felt cast adrift. I feel if they had told me more it would have increased my understanding of how medical professionals deal with this. I have had some relief over recent years reading other people's life stories to do with contaminated bloods. I know now that I have not exaggerated aches, pains, feeling etc. I do not feel so lonely now.

### **Section 7. Financial Assistance**

50. I received a winter fuel allowance from Caxton as a one-off. I think I might have got £500 this one year. I'm not sure of the amounts. I also recall getting a grant for large pieces of furniture and this may have been around about £6000. They also paid off my debts and it was generally quite an easy process.
51. I received £20,000 from Skipton in 2004 and a further payment from the Scottish government of £30,000 in 2016. I found Skipton to be an easy process as well.
52. I have found the new Scottish Infected Blood Support Scheme to be easy. I received an income top-up for a couple of months. I mark myself as severe and I'm receiving £18,900 per year which amounts to about £1,575 per month.
53. I believe the compensation amounts should be larger and there should be a one-off payment. I don't think there should be anyone getting more money than someone who have been infected. I don't think health categories for stage 2 are wide-ranging enough and there should be other criteria other than the liver damage that has been done. I do believe that there should be more compensation for psychological and neurological effects.

**Section 8. Other Issues**

54. I was not involved with the Penrose Inquiry. I think I really just tried to forget about everything at that time. If I didn't think about it then I wouldn't worry as much. I was very much focused on my family at the time of the Penrose Inquiry. I did not want them to know and I was scared about letting people know. I was scared about other people's ignorance about the condition. I even remember when I got pregnant

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55. When I received payment from the support schemes, I had huge issues with the job centre and the DWP. They said the money I had received counted as savings because I received benefits, even though I showed them the waiver from the various support schemes. I appealed the decisions that were made and received a support with this. I find it upsetting that this appeal was required in the first place. I exhibit a letter in relation to this as **WITN2147015**. I now receive PIP payments. I recall one day, I went to hand in personal information and I was handed back forms from someone else's case. There seems to be no sense of security in terms of keeping documents safe.

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**Statement of Truth**

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

Signed GRO-B \_\_\_\_\_

Dated Feb 10, 2021