

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN5943001

Exhibits:0

Dated: 29 April 2022

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 24 August 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1937 and my address is known to the Inquiry. I am a retired teacher. I live alone and I have 2 sons and 1 daughter.
2. I intend to speak about my infection with Hepatitis C (HCV) virus. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it has had on my life.

Section 2. How Infected

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3. In December 1985, I had a hysterectomy at GRO-B I don't remember much about that time or if I had a blood transfusion, but I remember that I was anaemic before the surgery due to heavy bleeding.
4. I spent 11 days in hospital following the surgery. I was off work for about 3 months and I made a full recovery from the surgery. I do not remember getting any information about any risks of possible infections prior to or after the surgery.
5. I understand that it was following this surgery that I became infected with HCV. However, it was not until 2009 (24 years later) that I found out I had been infected with HCV.
6. In December 1993, I developed a severe flu-like illness. I was given 3 courses of medication, which I believed to have been antibiotics, at this time. In early 1994 I had various blood tests, some at GRO-B Hospital, GRO-B which at that time specialised in viral diseases.
7. I was told there was a virus present in my blood but it was not identified. Later, I was told I had Myalgic Encephalomyelitis (ME). Afterwards, I had little or no energy and because I was unable to work, I had to take early retirement in 1995.
8. There was no known cure for ME and many people did not believe it was an illness at that time. I was told to do what I could and not to overdo things. As there was no medical help for ME during this time, I bought books on ME and tried to find out what was known about this condition. A lot of the symptoms certainly matched those that I had. After reading, I thought that pacing myself might help a bit which it seemed to at times.
9. For the following 3 years, I was unable to do much and just existed. Then I went through a period of many years having swings of energy, sometimes being active and thinking I was getting better, followed by a trough where

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the great lack of energy returned and I found it hard to just look after myself.

10. It was difficult finding a pattern for my illness. I tried keeping a diary but the illness proved to be unpredictable. I found that after being more active I had aches and pains around my body. Also, after being active, I had brain fog and my tinnitus became much louder. When I was outside, I found traffic noises and bright lights overwhelming.
11. In the years between 1995 and 2009, when I believed I had ME, I suffered from a great loss of energy, dizziness, brain fog, flu-like aches and pains, discomfort in bright light, traffic noise and tinnitus, which increased in intensity, depending on stress levels. Trying to do physical things (housework, gardening for example) were difficult to finish before I had to go and rest. I also had periods of acute anxiety and depression.
12. There were periods where I thought I was well. At those times I pushed myself to get back to "normal" but it was always followed by periods of feeling utterly exhausted and finding it difficult to do everyday household tasks.
13. I found out about my infection with HCV because I had gone to the GP with floaters in my eyes and I had been feeling unwell. The doctor ordered a blood test which showed up an abnormality. After more tests, they discovered I had HCV. This was 24 years after I had been infected.
14. Dr. GRO-B at GRO-B discussed with me the way HCV was transmitted and the only way it could have happened to me was through a blood transfusion. As I remembered I was anaemic before the operation in 1985, that was the likely time I had a transfusion. We did not discuss whether the ME symptoms were due to the HCV. The focus was on getting me to see the specialist in the liver clinic.

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15. When I first got the diagnosis, I was confused, though I knew HCV was a serious illness I did not know any details. I knew that because I was having to see specialists it was serious, but at that time I thought there was a cure. I was a bit anxious and bewildered.
16. I was then referred to the hospital by my GP, in relation to my HCV diagnosis. From that point, I received information, help and treatment for the resulting condition caused by the HCV. When I started attending the liver clinic at Ninewells Hospital, Dundee, I had an ultrasound scan, fibroscan, and blood tests were taken. I also had to have vaccinations against Hepatitis A & B. I also had an endoscopy.
17. I was told about the nature of the illness and the treatments they had at this time. It is hard for me to remember details as at the same time as I was dealing with this illness, I was also dealing with my mother's illness and taking her to hospital and doctor visits.
18. After speaking to Dr GRO-B and knowing the only way I could have got HCV was through a transfusion, I felt I must have had one when I had my hysterectomy. On 19 June 2009, I received a letter from Jan Tait, Clinical Nurse Specialist Gastroenterology, at Ninewells Hospital, Dundee, that she had received confirmation from the Blood Transfusion Service that I had received a blood transfusion. This confirmed in my mind that I had become infected with HCV as a result of a blood transfusion 24 years previously.
19. I was most likely told about my risk to others at the clinic, but I don't remember being told this. It was a lot to take in when I became aware of my situation in 2009. I went online and found out more about the horrendous disease I had been infected with. I urged my children to get tested which they did and fortunately their tests were negative.

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20. More recently, I received my medical notes and they supported most of what I had managed to remember through my personal papers and calendar notes, about how I came to be infected with HCV.
21. In the medical notes, I found a letter sent by [GRO-B] Consultant Obstetrician and Gynaecologist, confirming that I had received 2 units of blood in the course of a total hysterectomy operation carried out at the Gynaecological Unit at [GRO-B] on 11/12/1985.
22. A letter sent by [GRO-B] states that he thought that my "persistent symptoms are entirely consistent with a post-viral fatigue syndrome." He also states; "I have taken blood today for LFTs (Liver Function Tests), Random Blood Sugar, ASO titre, CRT as well as Lyme serology." This was dated 23/06/1994.
23. A letter from 2009 from Dr [GRO-B] to Dr [GRO-B] at the Gastroenterology Clinic at [GRO-B] refers to the tests in Dr [GRO-B]'s letter by saying she could find "no results for these tests in our notes, nor of course on Central Vision." She also states "Mrs [GRO-B] does report that over the course of her post-viral fatigue, which persisted for many years and, indeed, precipitated her retirement from work as a teacher, she had intermittent episodes of yellowish discolouration of the skin."

Section 3. Other Infections

24. I do not think I received any other infections. After being diagnosed, I received many tests ruling out HIV and other illnesses from a very supportive team at Ninewells.

Section 4. Consent

25. I do not recall being asked to consent to the blood transfusion I received in 1985. I do not remember much about this time, but I think if I was conscious, I would have remembered being told about requiring a blood transfusion before or after the surgery.
26. Since 2009, from the time I saw the GP about the floaters in my eye, I have had everything explained to me and I have given consent to the treatments I have received.

Section 5. Impact

27. As mentioned above, I was shocked to receive the HCV diagnosis, as I had been putting down my poor health and various symptoms to ME. I felt aggrieved that I was ill all these years without knowing what was wrong with me and that I was a possible risk to my family and others for years.
28. I only told my close family and friends about my diagnosis with HCV, and made sure I told my dentist and any other person who had to treat me. I also made sure when I cut myself, I kept the wound covered until it healed. It also made me feel inhibited about hugging and kissing my family.
29. I think that information and support should have been given years earlier. It seems to me that whenever it was known that this blood was contaminated and causing such serious and fatal illnesses, there should have been a major effort to find those who had been infected and to give them support.
30. Following my diagnosis, I initially saw Jan Tait, Hep C Nurse Specialist Gastroenterology Unit, at the Liver Clinic at Ninewells Hospital, Dundee, who explained about my condition. There I was given blood tests, fibroscans and an endoscopy over a few visits. After that I met Dr Dillon,

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Consultant Gastroenterologist Ninewells Hospital, who explained the results of the various tests I had been given, including the ultrasound scan at PRI. During this time, I was told I had some scarring of the liver.

31. In September 2009, I was told I had Genotype 1 Hepatitis C. I delayed treatment as where I live would have made it difficult to get to clinic appointments through the winter and then, in February 2010, my mother had a serious heart attack and I had to look after her. The clinic was GRO-B miles away in Dundee.
32. In August 2010, I went on to the 48-week treatment of Pegylated Interferon which I had to inject weekly and Ribavirin tablets taken daily. I got weekly, then fortnightly, then monthly blood tests. I was told about the possible side-effects of the treatment and the possible success rate to get rid of the virus.
33. The treatment intensified the flu-like symptoms I had already been suffering from, caused a horrendous itch, nosebleeds and soreness from the injections. Other symptoms were sore throat, sore ears, painful muscles and joints, headaches, palpitations and shortness of breath, all of which came and went.
34. Unfortunately, this treatment did not clear the infection. Some of these side effects are still with me, including nosebleeds, brain fog, very dry skin, painful joints and muscles, and weakness/lack of energy.
35. I found out that the treatment wasn't working before it ended. The viral count was not reducing as hoped and so it was stopped after 24 weeks on 07/01/2011. I was naturally disappointed but had mixed feelings as the side-effects had been so unpleasant and it was a relief to stop the medication.
36. Between 2011 and 2014, I was offered 2 other HCV treatments which I declined because part of the treatments included Interferon and Ribavirin which had failed to work previously and, there were possible serious side-

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effects. I was already having to deal with the disease and the side-effects of the first treatment and did not want to try either of the treatments, Boceprevir and Telaprevir.

37. I also learned that my liver had become scarred as a result of cirrhosis caused by the HCV. As I mentioned above, I was told about the scarring following my fibroscan. I cannot remember how often I got fibroscans but it was on a regular basis. As I said since I was introduced to the clinic, I felt very assured that everything possible was being done for me. The fibroscans and ultrasound scans were painless. I found and still find the endoscopies cause me anxiety and are quite traumatic.
38. In 2014, I had a heart attack from which I made a good recovery. However, the follow-up program of exercises went well for a while and then steadily declined as my energy levels fell and I had to give up the exercises. I had blood tests and was told my thyroid was under active and was started on Levothyroxine. Coincidentally, one side-effect of interferon is thyroid problems.
39. In 2015, there was a new treatment called Harvoni which I was offered and started a 12-week course on 07/12/2015 and finished on 28/02/2016, results to be known 6 months later when tests would show if the virus was present.
40. In 2016, I became seriously ill when varices (caused by the malfunction of the liver) burst and caused a major crisis. On 05 April 2016, after completing the Harvoni treatment, I was feeling very unwell and was vomiting dark brown liquid, which later proved to be blood.
41. I was taken to GRO-B and then to Ninewells, where it was discovered that varices had burst due to the cirrhosis caused by HCV. I was very ill with this, needing blood transfusions. I naturally felt devastated because this meant the disease had damaged my liver more than I had thought. It led to me becoming very depressed and anxious.

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42. In August, the results from the Harvoni treatment showed that the virus had been cleared, sadly not before major damage had been done to my liver and to my overall health.
43. As mentioned above, getting to the clinic appointments in Dundee (GRO- miles away) was difficult especially in winter, when I was having the first treatment in 2009. Some years later, a liver clinic was opened in (GRO-B) and then appointments were mostly in (GRO-B). My son took time off his work to take me to most of the appointments over the years.
44. I do believe that any treatments available at this time were offered to me and I was not denied any treatment over the years.
45. The most significant mental effects of the treatment were and are bouts of extreme anxiety and debilitating depression, knowing I would have this for the rest of my life. The strain of having to deal with all the treatments, procedures, blood tests and results to do with HCV also caused and causes much anxiety and distress.
46. The physical effects were and are lack of energy, brain fog, aching joints and muscles, nosebleeds, occasional shortness of breath, palpitations, dry itchy skin and tinnitus, and great disappointment in not being able to do many of the things I enjoy. All the time and efforts made over the years dealing with HCV and getting to and from clinics, spending many months on treatments and getting over them, and spending time in hospital and recovering afterwards has robbed me of time I could have spent in normal, happier pursuits.
47. I have very little energy a lot of the time, have joint and muscle pains, brain fog, nose bleeds and often cannot finish simple jobs that I have started (e.g. basic housework tasks). Also, I have a lot of anxiety about the illness, wondering what the next stage might be. These are no doubt exacerbated by getting older.

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48. I don't think my infected status has impacted on my treatment for any other conditions. The ME diagnosis was never discussed with any of the doctors and nurses at the clinic. There was always more pressing topics of dealing with the HCV to talk about. My health now is still governed by the results of having HCV.
49. After I was diagnosed with cirrhosis of the liver and suffered with varices, I became an HCV Stage 2 beneficiary from the Skipton Fund, due to the severe impact the HCV had on my health.
50. Since then and up to 2020, I have had regular endoscopies, ultrasound scans and blood tests and visits to the liver clinic at GRO-B and Ninewells. After March 2020, because of the pressures of Covid-19 on the health service, I have still had endoscopies but not the ultrasound scans and other contact.
51. I am concerned that Covid-19 restrictions has interrupted some of the treatments and clinic contact I was getting but, I am just one of many thousands of people in the same situation. I am grateful that so far, the clinic has managed to keep regular endoscopies going as they are a vital part of the ongoing treatment. I do worry that by not getting ultrasound scans and other routine tests that my liver health could worsen.
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52. I cannot say that I have suffered from stigma in relation to my HCV. My children were all adults by the time I was diagnosed with HCV and my family and friends were all very supportive. I didn't experience any stigma towards me. The biggest impact for me was being unable to work and do the things I enjoyed, because of the lack of energy and the many bad effects of having HCV. I have missed seeing my granddaughter as much as I would have after being in hospital in 2016. I felt unable to tackle the long distance to visit family in London and Edinburgh.
53. When I knew I had HCV, I was already retired, having to stop work early due to illness. I had a part-state pension, a part-work pension and a small overseas pension and up to retiral, I had invalidity benefit. The latter was

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stopped after a visit by a doctor sent by the Department of Work and Pensions who spent a short time with me. I was having a "good day" and was a bit hyper due to anxiety. During the brief visit she told me that "ME was the new sore back syndrome" and my invalidity benefit was stopped on my 60th birthday. This made me more anxious and wonder if I was a hypochondriac. I had enough to live on but not enough to do extras like much-needed house maintenance and other things I had planned to do when I retired.

54. Since my diagnosis with HCV and subsequent treatment, I feel a lot more anxious about any type of medical treatment I need to have as a result of what I have been through.

Section 6. Treatment/Care/Support

55. Initially, after the HCV was discovered, I had no difficulty receiving tests and treatment as detailed above. However, since 04 September 2020, I have not been receiving ultrasound scans due to the Covid-19 restrictions.
56. I was offered counselling from the Scottish Infected Blood Support Scheme (SIBSS), but had on 2 occasions obtained counselling through my GP to help with anxiety. I have not taken up the offer for counselling specifically through SIBSS. It was not practical for me during lockdown and knowing how stretched the NHS is to make such a request.
57. I have had no difficulty getting dental treatment since my HCV diagnosis.

Section 7. Financial Assistance

58. On 16 September 2009, I was told by Dr Dillon, Consultant Hepatologist at Ninewells Hospital, Dundee, that I had Genotype 1 Hepatitis C. I found out about the Skipton Fund through his clinic. I applied and was given a lump sum.

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59. The team at Ninewells gave me the Skipton Fund forms. Once my claim had been checked out, I received the payments. The Skipton application was straightforward. I did not have to provide medical records. I assumed the clinic at Ninewells hospital did that.

60. From the Skipton Fund, I received a first stage payment of £20,000 on 29 March 2010 and a second stage payment of £50,000 on 31 May 2016. Since 13 May 2016, I also received monthly payments from the Skipton Fund. These payments were taken over by Scottish Infected Blood Support Scheme in March 2017.

61. Apart from the Skipton Fund, I have not applied for financial assistance.

62. I am unaware of any pre-conditions for applying for financial assistance.

Section 8. Other Issues

63. I made a statement on 24 October 2010 for the Penrose Inquiry. A representative of the Penrose Inquiry visited me and asked questions and they put together a statement which was submitted to the inquiry.

Statement of Truth

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

Signed

GRO-B

Dated

29 April 2022