ANONYMOUS

Infected
Blood
Inquiry

Witness Name: GRO-B
Statement No.: WITN2097001
Exhibits:
Dated: 28 January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 November 2018.

I, GRO-B will say as follows: -

1. Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry. I am infected with Hepatitis C, and now have stage four prostate cancer. After Interferon and Ribavirin therapy, I previously contracted colon cancer and had a colectomy, and now prostate cancer. I intend to speak about my condition and living with Hepatitis C. In particular, the circumstances of infection, the nature of my illness, how the illness has affected me, the treatment received, and the impact of both Hepatitis C and the treatment has had on my wife and I, and on our lives together.

2. How Infected

2. In June 1974, I was working offshore on an oilrig moored some distance from the coast of Scotland. I was in charge of bringing in all supplies including drill pipes, provisions, and drilling chemicals from the supply barges onto the rig. I oversaw and was in charge of a twelve/man roustabout crew.

3. One morning in April 1974, I was working on the deck, taking drill pipes from the barges. Whilst I was working on the deck, the crane operator had fallen asleep and a three tonne drill pipe swung towards me very quickly, lifted me off my feet, and pushed me towards some vertical pipes. The three-ton pipe crushed me against the vertical pipes. The subsequent injuries I sustained were a broken hip and pelvis. (left acetabulum and inferior pubic ramus) as well as left arm and pelvic abrasions and cuts. I lost a considerable amount of blood as a result of the accident.

4. I had been told I was unconscious immediately after the accident and was given morphine or a similar painkiller. The next event I recall was waking up in Foresterhill NHS Hospital, Aberdeen, the next day.

5. By the time I regained consciousness I had been given a blood transfusion and my pelvis was immobilised and in splints and my left leg was in traction. I stayed at Foresterhill Hospital for three to four weeks. I was then transferred to GRO-B Hospital which was close to my home, where I lived with my wife.

6. Throughout the duration of my time at both hospitals I was not informed that I had been given a blood transfusion, and neither was my consent sought for one. The doctors who treated me provided me with little to no information about what had happened to me after the accident, the extent of my injuries, and most importantly the blood transfusion. It was only years later, in 2003 when my GP in GRO-B had looked at my

medical records, that I found out that I had received a blood transfusion . I received 8 or 10 units of blood, some parts of which were infected with HCV.

7. Upon leaving the hospital I had to learn to walk again. However, no support was given to me by way of physiotherapy, and I was only told to contact my GP for support.

8. Upon being discharged from the hospital, my health was relatively good. However, two to three years after the accident I started to develop intense itchiness and erythema across my whole body. Both came on slowly, but increased with severity each time. I had to cover myself in calamine lotion and have cold baths at night, in order to be able to sleep. I also felt constantly fatigued. At this point I continued to see my doctor, who thought I had Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (ME). As the symptoms increased, I suffered from constipation and right-side inter-costal and abdominal pain.

9. For these two – three years, I was unsure what was wrong with me, however, I decided to go back into education after working in the oil industry. With this in mind, I applied for a 3-year place on the Diploma in Community Education course, at a local teachers Training College, (now Dundee University). I completed the course in three years, and graduated in 1979/80. Throughout this period, the symptoms continued to manifest themselves in different ways. I would either have diarrhoea or be constipated. I would also have severe brain fogs at times and continuing tiredness and fatigue. This made it very difficult for me to concentrate on classwork, placements, and exams.

10. After graduating, I decided to become a trainer in either the voluntary or statutory sector. After a year out, in which I looked for employment, I was employed firstly by GRO-B, a voluntary sector Arts organisation. After two years working there in charge of eight staff, I applied for a job as Training Officer in GRO-B. I was interviewed

and employed. My employment there started in late 70, early 80's. My occupational remit within GRO-B, was to work in both the adult education sector, working with GRO-B staff, and to deliver direct training courses to trainees. The HCV symptoms continued to increasingly hinder my ability to carry out my work there. For example, sometimes, whilst I was delivering courses, I would feel that my whole mental operating system and some of my awareness (especially cognitive faculties) had been erased. This caused me endless stress and worry. When I suffered with these 'brain fogs' I would not know where I was in the schedule of training delivery. For example, it would be difficult for me to know how far into the course we were and I would experience bouts of severe amnesia. As a further example, I would not remember the last words that I had said to the trainees. I found this increasingly terrifying, and it filled me both with increasing anxiety. Despite my efforts to hide the symptoms, I recognised that I would not be able to continue working in my professional role for much longer.

11. I had informed my GP of my developing symptoms during the intervening years, however they continued to tell me that I was suffering from ME. They did not treat me for this, but said they would continue to observe me; which they did for many years following. As my condition worsened, the medical profession recommended that I go to a psychiatrist, which of course did nothing for my HCV infection. I became increasingly ill, and I started to take more days off work. I would feel intense pain in my shoulders, limbs, and joints. This pain was intolerable, and it soon became difficult even to raise my arms to shoulder height. The attendant pain in trying to do so was excruciating. I then began getting severe headaches, increasing memory loss, and more joint pain. I kept going back to the GP, however they did not order any liver biopsies or any further tests.

12. In 1999, I thought that I might somehow have contracted HIV. In those days I did not know much about it, and had never been involved in any form of activity that would have increased my chances of contracting this. I

was just aware that something was terribly wrong with me, and I was increasingly compelled to find out the cause.

13. I insisted that my GP find out what was wrong with me and requested they order comprehensive blood tests. Some months later, I received a letter saying I needed to come to Raigmore hospital for my Hepatitis C results. I was not aware I had been tested for Hepatitis and only thought it had been for HIV. The letter suggested I make an appointment. I did so, but was informed on the phone, that there was no need for me to rush to see the doctor. This laid my mind to rest a little, as I imagined that it was not a serious disease. Subsequently I researched the disease on the internet, and was appalled at the legacy and the severity of HCV infection. I was further traumatised, and realised that they were 'playing down' my disease, because there were no cures at that time. After several months more, I received an appointment date with a senior consultant at Raigmore Hospital, Inverness.

14. Upon seeing Dr GRO-B, the Senior Gasteroentolgy consultant, I was informed I had Hepatitis C, but was told there was nothing that could be done about it. I was informed that the 'treatment' was for me to be kept under observation only. The doctor did explain that Hepatitis C was a virus that attacked the liver, however it was not explained to me how I was infected or about its severity and prognosis for a victim. They asked me if I had ever been involved with intravenous drugs or heavy alcohol use. I told them truthfully, that I had not.

15. I requested bereavement counselling from my GP. At that time the disease was considered terminal, and I did not know what to do or how to cope with it. Later, my GP offered to put me in contact with a gay/transvestite counselling service, offering counselling. I could not understand how this was relevant to my Hepatitis C infection, so I did not engage with them. Unfortunately, this was the only type of counselling service available locally for these types of diseases, (presumably HIV and AIDS) at the time.

16. I then undertook a lot of independent research via the internet. I found that my genotype was the ‘best one’ for sustained HCV viral response using Interferon & Ribavirin treatment. As my condition progressively deteriorated, I knew that I had to find as much information as possible about this disease; and whether there was any possibility of it being cured or symptoms lessened. I gave the consultant a number of documents about all the different tests, trials, and differing world-wide genetic responses (or otherwise). When I discovered interferon allied with ribavirin as an anti-HIV regime, I thought that I should push for this treatment. The doctor eventually agreed to enrol me in a trial.

17. I was the first person in the GRO-B region to be given Interferon and Ribavirin and the first to respond. I was prescribed a 12 month course of this treatment. The side effects were terrible. I would often shake, sweat, my teeth would chatter, and I couldn’t breathe. I would have to lay in bed with blankets over me and an electric blanket switched on, as I felt extremely cold. It was very difficult for me to sleep at night, and I found that I could lessen my reaction to the drugs by eating late at night before I injected myself.

18. I don’t believe that anyone, medical staff or otherwise, recognised or acknowledged the psychological problems associated with Hepatitis C. I would often have fits of irrational rage, become irrationally argumentative, and have irrational mental responses to anything said or implied by anyone.

19. Loud noises became intolerable and I would also suffer from severe sadness and depression. I often wondered whether I should take my own life, because the suffering seemed never-ending.

20. I started treatment in 2000 and finished in 2001. After my treatment had finished the consultant did not tell me that I had to go for any regular

check-ups or for regular biopsies or for regular ALT/AST liver 'transferase' tests afterwards.

21. In 2001, after the treatment had been given, I was informed that I had undergone a sustained viral response and that the virus was now absent. I was very pleased about this, however, after the treatment I did not feel like the same person mentally, or physically. The constant joint pains, fatigue, and lingering psychological effects had taken a toll on me, and those physical and mental problems have persisted to this day.

22. It was only in 2003, when the Caxton Foundation contacted me, and I had access to my medical records that I realised that the cause of the Hepatitis C infection was the blood transfusion I was given in 1974.

3. Other Infections

23. After about a year after finishing Interferon and Ribavirin, I noticed that I had blood in my stools. I was admitted to Raigmore Hospital, where they found out after colonic biopsy, that I had colon cancer. I underwent a colectomy and recovered from this. However some 18 years later, I noticed blood in my urine, and again after biopsy at GRO-B GRO-B GRO-B (where I now live) was told that I contracted stage 4 prostate cancer.

4. Consent

24. I maintain and assert that I was never asked for my consent or told about the blood transfusion, nor given information about being given blood products after the accident occurred.

5. Impact

Career

25. I stated earlier that I was originally employed as a supervisor on an oil rig. I decided to leave offshore work, because I thought it dangerous and that health and safety practices and training were very lacking, and I was too nervous to continue in such a career. Later, I was employed as a Training Officer by GRO-B. I delivered training to GRO-B staff, worked with disabled and disadvantaged clients, and was employed as a trainer with youth training services (then YTS) delivering vocational qualifications.

26. Due to my Hepatitis C infection, as I previously said, I began to suffer from severe amnesia and brain fogs. This made it very difficult for me to remember my work, and I would have to stay up every night to make detailed course notes – as I would often forget where I was in the lesson plan and sometimes had no memory at all of what the last words that I had given to the various trainees were..

27. I had a large number of sick days, and they were increasing. My sick leave record was becoming terrible and I recognised that I was becoming unfit for employment. All due to my HCV infection.

28. I worked at the GRO-B for nearly three more years, and during this time, undertook in-house training, and external training qualifications, to increase my employment prospects. These, due to my previous HCV status and the legacy of my infection, were very hard to complete. However I qualified well in all of the courses that I undertook, and became the highest qualified trainer in the training organisation. I had ambitions of going into the training sector in the oil industry, as this would have been well paid. I obtained two more qualifications, however I feel my illness and its ongoing legacy was a severe barrier to my professional progression and employment aims.

29. I had to give up all my employment in 1982-83, as my health had deteriorated severely. I was also forced to give up all my career ambitions and then believed that I was unable to fulfil any of my career potential. I

believe that as a trainer with my qualifications, that I would have earned a salary of circa £40,000. Further, in the oil industry, I would have been able to earn between £60,000 / £80,000 per annum. My out-of –house training service days (to outside organisations during the 80's) were costed at circa £500.00 per day whilst working for GRO-B

30. I am qualified in Community and Adult Education (Dip. Comm. ED.) aswell as owning Training qualifications (Direct Training) and also Training of Trainers qualifications. I lost all of this future income and career path, the entailed pension, and salary-related pensions and entitlements, as well as SERPS pension-benefits, because of lack of care provided by the National Health Service and its demonstrable dereliction of duty of care to myself.

31. I believe that my loss of salary over the intervening years is in excess of a million pounds, plus earnings from related pensions and SERPS – because of what I believe to be medical incompetence.

32. In the early 2000's, because I was unable to live on incapacity benefit, I set up my own business selling guitars, amplifiers and speakers and other musical instruments on-line. I imported these items from Korea, Taiwan, and China. I chose to work at this business because it involved exerting manageable amounts of energy to the task, as well as my being able to work from home. My partner at the time could also assist me with figures and invoicing, as I found numbers as well as admin. and customer relations and liaison, to be very difficult for me.

Physical and Psychological Effects

33. In the beginning, the Hepatitis C caused me intense itchiness and Erythema across my whole body. I also felt constantly fatigued, suffered with brain fog, and severe amnesia. As I have explained above, this hindered my ability to carry out my work GRO-B. As a consequence, I had to give up all outside work and employment.

34. Moreover, as I have set out in more detail above, I suffered with severe pain in my shoulders, limbs and joints. The pain was intolerable.

35. The impact of my HCV infection was not confined to just physical difficulties. The Hepatitis C caused me ongoing psychological problems. I would often have fits of irrational rage, be argumentative, and have irrational mental responses. I also would suffer with sadness and depression, and sometimes contemplated taking my own life.

Treatment

36. Once I argued for and received anti-HCV treatment and was enrolled in a drug trial at my insistence, the side effects of interferon and ribavirin caused me to shake, and sweat, and my teeth would chatter. I felt as if I could not breathe, and I would often lay in bed with multiple blankets and an electric blanket on, as I felt extremely cold.

37. I currently have stage four colon cancer diagnosed in GRO-B in September 2018. I believe the more than doubling of cancer rates in Hepatitis C victims, in comparison to those without the infection is evidence that my cancer diagnosis, is directly linked to HCV and therefore directly to my contaminated transfusion.

38. As I have set out above, it was only due to me putting pressure on the HCV consultant subsequent treatment with interferon and ribavirin was given. I studied the clinical pathology of HCV in depth and argued that I should be given interferon-ribavirin, as I had a good chance of combatting my HCV genotype. I would not have been offered any support or treatment without my putting pressure on the doctors and consultants, or at least not at that time, although possibly later. I was always under the impression that HCV treatment was expensive, and that it would affect the relevant NHS budgets.

Social/Private Life

39. The Hepatitis C, treatment, and side effects have led to my having a non-existent social life. Only very few people knew I had Hepatitis C. I spoke with my family about it, and they felt complete sadness for me.

40. I had my first son, GRO-B, in 1973. I was with my first wife GRO-B GRO-B and we were living near GRO-B in Scotland, which is where I lived when I was given contaminated blood. Our relationship broke down due to my HCV infection. I believe this was due to my symptoms and the condition to which I had deteriorated. Following our divorce, in 1978, she died from Hepatitis C with which I had infected her, despite not knowing that at the time. I was made aware of this much later. At the time of her death we were not together, so I knew very little about the circumstances of her death. I was only in regular contact with our son GRO-B, who was with her when she died.

41. I met my second partner GRO-B and had my second son GRO-B in 1981. However during this period I became increasingly ill. I could not cope alone with childcare, and we had to hire a nanny. My partner was a senior social worker in GRO-B She had to retire early to look after me – as I then required continual support. When I was told that I had a sustained viral response to HCV infection, this coincided with GRO-B's parents dying GRO-B then wanted to move back to Wales, so we sold our home in Scotland. We struggled to find a property in Wales within our budget.

42. At this point I wanted to go and live a sunnier and warmer climate. I could not cope with the wet and miserable weather in Wales. My joints were now aching even more, because of the HCV infection and the cold. We came to GRO-B because of the better weather, and the lesser cost of living. I could not afford to buy a house in the U.K. My move to GRO-B was directly related to the infected blood I had received and the following severe illnesses and ever-present symptoms relating to ribavirin and interferon therapy.

43. After I gave up work in the U.K, I was in a position where I could not afford to put a deposit down on a house, and with only incapacity benefit as an income, could not get a mortgage – despite my business selling musical instruments, which became quite successful.

44. My partner at the time and I took a short holiday in GRO-B and thought about moving there. It would have been impossible for me to look after myself on my own, but GRO-B, did not like the lack of infrastructure in GRO-B, and wanted to live in Wales to be with her friends and remaining family members. We decided that I would stay in GRO-B and she would live in Wales with our son GRO-B Some years later, GRO-B became severely ill after contracting Addison's disease. She passed away in GRO-B 2017.

45. Having Hepatitis C has also impacted the relationship which I have with my sons and their view of me. During my infected years, they constantly saw me in bad moods – and because of the irrational anger that often came over me, they thought of me as a weak and ill person. I think that they did not realise the legacy of the disease, and thought that my mood-swings and exhibits of a difficult personality was 'just me'.

46. I met GRO-B in 2015, and we have since got married. GRO-B cares for me full time and presently has to take me 160 kilometres to hospital every day for radiotherapy treatment. I am also on chemotherapy treatment. She looks after me at home and provides emotional support. I am of the firm opinion very few wives could put up with the problems and situations that GRO-B does – especially with my mood swings, anger, and aggression. There is no root cause for my behaviour, and it is my strong belief that it is due to the fact that I am again severely ill in addition to the on going side effects of Hepatitis C and the treatment I received for it.

47. The mood-swings continued after anti-HCV treatment and long before I was diagnosed with my recently diagnosed stage 4 prostate cancer.

6. Treatment/Care/Support

48. I have set out above, in more detail, that treatment of interferon plus ribavirin was only given to me after I had pressed the doctor to enter me into a drug trial. When I was initially diagnosed with Hepatitis C, the doctor did not advise or provide me with any course of treatment. I was only told I would be kept under observation.

49. The only counselling service I was offered was for gay and transvestite men, and I did not think this was relevant or would help me. Previously, I had been recommended to a psychologist before I was diagnosed, but her interaction merely focussed on the relationship that I had with my mother. My GP at the time still imagined that I was either suffering from ME or malingering. I have never had psychological support for having been given Hepatitis C since then, and no one has ever contacted us regarding support or for any strategy planning since.

7. Financial Assistance

50. Since I was forced to give up work as a trainer, I have lived on incapacity benefit, and later (as I found it impossible to live on such a low income) I set up a small business, as explained above.

51. I received a cash settlement of £6000 from my employer, (GRO-B) due to the accident on the oilrig. I currently get £42.00 a month from GRO-B, for the short time I was employed there. For a long period of time I lived on £56.00 per week incapacity benefit.

52. We have received some financial support via Caxton. The support given by Caxton was around £208.33 pounds per month. I was never told about them, but discovered them through the Hepatitis C Trust and then applied for financial assistance. I received monthly support from Caxton when I was single, and later after GRO-B and I got married. We applied for several different grants during this time for help with furniture and fixtures, and got

some monies for laminate flooring and I also received mobility grant towards a car.

53. For a number of years, as I said above, my wife GRO-B and I were living on my incapacity benefit of £56.00 a week. We had to subsist on only had a single person's allowance. We were very poor and found it difficult to live. We could not even afford to buy second hand clothes, and all we could afford to buy new was socks.

54. There were a number of occasions where Caxton refused to help us financially. For example, when GRO-B and I got married, I could not afford a wedding ring. I asked Caxton if they could assist me in this regard, and was told that there was no budget for expenses such as wedding rings. A little later, after our marriage, I requested money so that GRO-B and I could go away on a short honeymoon – I requested enough for two to three days stay in a hotel. However, Caxton informed me that there were no grants available for this. I then argued that the money was for very brief respite care for GRO-B This would be a few days rest for her, when she would not have to wash and cook and clean and to look after me all the time. Despite this, they continued to refuse us assistance.

55. I signed a new agreement saying I was happy to move over to the Scottish Infected Blood Scheme-NSS (SIBS). In May of 2017, we switched to their payment system and then received, (as now) £789.50 per month, as a married couple.

56. Currently, we have £17,500 total income including OAP pension, plus £1000 for heating and winter supplements. In total we have £18,700 a year, or £1,200 a month. This money however is not sufficient, as I now have to pay for all my medical supplies and pain killer patches and injections, which I am prescribed by the GRO-B health system. At present, we have to pay around €250 a month for my healthcare costs including travel every day. I applied to SIBS for help, as I thought that it was discriminatory that victims in Scotland were able to get free healthcare

and prescriptions, while I have to pay for my own. I stressed the point that the Scottish NHS had infected me, but I have received no reply at all regarding my query.

57. This seems to be an ongoing problem, however they have not responded to date, – even after having written a number of letters. I have informed them that we are disadvantaged, and that there is a distinct lack of financial provision and help for HCV victims, especially in my and our circumstances. I have always felt with both Caxton and SIBS, that I have had to consistently beg through applications and that I or we may or may not get a response.

58. The winter fuel allowance of £1000, we receive, if not enough to heat our home for six months in addition to paying for our medications and pain-killing drugs (morphine analogues) which I need constantly. I informed SIBS that I would therefore use the heating allowance money to offset my medical and our daily hospital travel costs for radiotherapy and chemotherapy. Recently, we received an additional £200 winter fuel payment via a U.K pension. In total, we have £1200 per annum, which will hopefully pay for our heating costs, and a proportion of our medical costs.

59. I now have stage four prostate cancer, as I said previously. The survival rate (at five years) is 29%. Therefore I am unsure if I will see the outcomes of the Inquiry, receive any proper support or solatium, and I very much doubt whether I shall ever receive any compensation for financial losses sustained and suffered during the whole working career that I have lost. I had to stop work in the mid-eighties, so I have lost more than thirty years of salary, plus earning related pension.

60. Another problem we have is that **GRO-B** my wife, is not eligible for carers allowance from the Scottish government. I am very concerned how she will support herself when I die. I have no savings. I am unsure how **GRO-B** will be able to access my death benefits and SIBS payments, as she does not speak very good English, and writes in English not at all. In addition, there

is little information available to us regarding what she is to do when I pass away.

61. I am going through the process of group litigation as a separate process, and am giving this statement to the Infected Blood Inquiry so that hopefully GRO-B can have something to live on for the rest of her life. She has been caring for me full time, and the ongoing prognosis is only getting worse, as my disease is incurable. I often wonder whether I will ever get full redress for getting Hepatitis C once, cancer twice, plus the ongoing effects of interferon and ribavirin, although the Scottish government has made some steps in that regard, and small additional recompense very recently. I realise that because of my personal circumstances, and the short time that I have left, that I shall only receive ex-gratia payments, and nothing else. I also recognise that because of the damage done to my health over the last 45 years since I was infected, that there is very little that we can do to improve our circumstances now.

62. I was diagnosed with colon cancer in September of the year 2000, and with prostate cancer in October 2018.

8. Other Issues

63. I take issue with the findings of the evidence-based review by Professor David Goldberg of Health Protection Scotland into the health impacts caused by Hepatitis C – commissioned by the Scottish government. In his review Goldberg refused to recognise fatigue as a common and ongoing effect of interferon and ribavirin therapy, and similarly, fatigue as a legacy of HCV infection. Further, he ignores that Hepatitis C victims are more than twice as likely to contract non-liver related cancer compared to others who have not contracted the disease.

64. I also take issue with the financial distinction made between those who are arbitrarily classed as Stage one and Stage two. It seems as if the Scottish Government and Professor Goldberg are taking sides opposing

us victims, and are trying to place one group against another, as well as to ring-fence budgets, and because of this, to deny us equitable and fair treatment under the law.

65. Unfortunately, now that I am at my lowest ebb, health-wise, I am unable to contest and to fight against what has happened to me, or to pursue due and fair recompense for being an innocent victim. After more than 40 years of having being infected, I am very tired and am now barely able to write or to argue my case. Now, after all this time, I do not feel that I am any closer at all to achieving either redress or justice, for being given this terrible disease.

66. I am unfortunately yet again suffering from yet another terminal illness and am of the opinion that there is very little that I can do, except to hope that the Inquiry will eventually lay the blame for ongoing NHS neglect of duty of care to victims like myself, where it belongs.

Statement of Truth

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

Signed

GRO-B

Dated: 28 January 2019