

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN0855001

Exhibits: None

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

1. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 19 March 2019.

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

Section 1. Introduction

3. My name is **GRO-B** born **GRO-B** 1942. I reside in **GRO-B** and my full address is known to the Inquiry. I am married, with two grown up children and I worked as a teacher prior to my early retirement.

4. I intend to speak about my infection with Hepatitis C ("HCV") through a blood transfusion. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and me.

5. I do not have legal representation with regards to the Inquiry.

6. The Inquiry Investigator has explained the anonymity process to me. I am aware of the option for my statement to be anonymous. I have elected to preserve anonymity due to the nature of my occupation as a teacher. Once my name is in the public domain, outside my control, parents of children I have taught may be unnecessarily anxious about the possibility of infection should they be aware of my statement.

Section 2. How Infected

Hepatitis C Virus

7. I believe I was infected with HCV following the birth of my son at GRO-B
GRO-B now known as GRO-B in April 1976 by way of blood transfusion. He was my second child. My daughter was born in 1974 at Southmead Hospital Bristol ("Southmead").
8. I had hoped to have my son by way of a natural birth, having had my daughter via caesarean section ("C-section"). The plan had been to allow me to attempt a natural birth. However, when I went in to have the baby on the agreed date, I was seen by a different doctor.
9. The doctor reversed the earlier decision. He thought there was a risk attached to letting me go into labour. Therefore, I ended up having a C-section for the birth of my son. In preparing to make my statement to the Inquiry I have obtained a copy of my medical records and it is only since reviewing them I am aware it was recorded as "elective". From my perspective it was coercive rather than elective.
10. I was upset needing to have a caesarean delivery. I was offered the choice of an epidural – which would at least have meant I was awake for the birth. In what appears to me to be a series of errors, the anaesthetist didn't receive the message to come and discuss this with me. I understand the junior doctor charged with passing on the decision said he "didn't think it was important". As a result, I was given a general anaesthetic. On 'coming round' from the anaesthetic my next memory is of hearing the baby crying and later opening my eyes to see a bag of blood hanging over me.
11. While I did not recall consenting to a blood transfusion. Since reviewing my medical records, I can see that while consenting to the C-section and anaesthetic, I also gave permission for the administration of "such further or alternative operative measures as may be found necessary..." Nevertheless, I was surprised to see that the hospital had given me blood. They did not give me any explanation or follow up about the transfusion. I only remember the nurse later taking the empty blood bag away.

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12. I have read my medical notes, and my understanding is that I lost less blood with my son's birth than I did with my daughter's birth. Despite this, I did not receive any blood during the birth of my daughter at Southmead Hospital.
13. After reviewing my medical notes, it appears that the GRO-B ordered the blood in advance. I find it interesting that I received double the amount of blood I lost. I lost one unit of blood was transfused with two units.
14. This leads me to question whether I really needed the blood transfusion, or whether the hospital just gave me blood in order to use up the supply already ordered for me.
15. A few weeks after the birth of my son, I remember having a raised temperature and other flu-like symptoms. I think my high temperature only lasted for about 24 hours. I do not know what caused it; I presumed at the time it was a mild viral infection. On reflection, it was possibly a sign that my immune system was engaged in the initial fight against Hepatitis C, but I was not successful in clearing the virus if that was indeed what was happening. At the time, I did not know that it might have been anything to do with Hepatitis C as the virus was not named and fully understood until 1989.
16. I believe it was the transfusion in 1976 after the C-section delivery of my son that infected me with HCV. I do not have tattoos and have never taken drugs or been treated in a hospital outside of England.
17. After my consultation with the specialist on the 26th March 2019, the HCV consultant confirmed the source of my infection in her report to the GP. The consultant told my GP "she clearly has been infected with hepatitis C since her blood transfusion back in the 1970s".

Diagnosis

18. I was diagnosed with Hepatitis C in December 2018, 42 years after I was infected and after many attempts to address health issues which have lingered throughout my adult life.
19. I am concerned it took so long to diagnose.

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20. After my son was born, it was a difficult period for me. We moved to a new house just a few weeks later, and my mother passed away shortly afterwards. We did not have enough money to meet bills in that period of high inflation, so I worked part-time in a pub when my son was one year old. I was absolutely exhausted all the time – I felt like I had been brought to my knees. I attributed my exhaustion to the fact that I had two young children and was working at the same time.
21. In hindsight I do wonder if the HCV exacerbated my fatigue. It is impossible to know the degree of tiredness I may have had anyway, so I cannot say exactly how much of what I was feeling can be attributed to Hepatitis C.
22. Looking back, I can see there were several opportunities for the HCV to have been picked up. By 1989 I was working full-time. My working environment was difficult at the time, but I believe that only partly accounts for why I was always lacking in energy.
23. In the early 1990s, I decided to see the GP as I was really finding things very tiring and challenging. My GP prescribed antidepressants, but she also stated that she could not "keep papering over the cracks" and that she wanted to find out what it was that was causing me to constantly feel drained. She prescribed counselling. I was not diagnosed with Hepatitis C on that occasion.
24. It was around the late 1980s when I began to have intermittent but significant pain in my hips. Eventually by 2008 I needed a left hip replacement and this was followed by a right hip replacement in 2012.
25. Towards the close of the 1990s, I first became aware of numbness in my toes. In 2009 when the discomfort had spread to my ankles and my balance was also affected, my GP referred me to a neurologist who diagnosed peripheral neuropathy with no known cause.
26. By 2018 the neuropathy had spread as far as my knees and I again saw a neurologist. Peripheral neuropathy – no known cause – was confirmed. The DVLA withheld the renewal of my driving licence pending a medical report. Fortunately, the neurologist testified that I was fit to drive and my licence was renewed for three years.
27. In 2006 or 2007, Anita Roddick, founder of the Body Shop, publicly discussed how she had contracted Hepatitis C through a blood transfusion at childbirth in the late 1960s.

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Anita Roddick's story resonated with me. I remembered that, like her, I had had a blood transfusion back in 1976 before blood was properly screened. That made me question whether I might have HCV.

28. I decided to raise my concern with the GP, but he merely asked me who Anita Roddick was. Other than that, I did not get any information from him; he just did not respond to my questions. That dismissive response was not particularly unusual from my then GP; sometimes I had to ask a question three times to get an answer. Despite this, the lack of response or concern from my doctor made me think that I was just worrying unnecessarily about possibly having Hepatitis C. I did not raise it with him again.
29. For many years I have bruised very easily, and it takes a long time for my bruises to fade. In 2012, in the tests before my second hip operation, it was noted that my "prothrombin and APPT were prolonged" – I now understand this was probably a sign that my liver was in distress. I was given a vitamin K injection the night before my operation to help my blood to clot, but it was unsuccessful.
30. In his clinical summary to the GP, the surgeon wrote that he had written to the haematologist at the North Hampshire Hospital to advise whether this needed further investigation and requested that the GP follow this up. Unfortunately, it appears that nothing was done at this stage. I don't recall that the GP did follow up on the orthopaedic surgeon's request. Possibly there was a breakdown in communication, because the hip operation was done at a private clinic, and the blood tests done at the North Hampshire Hospital would have been sent to the clinic. Private and NHS records seem to be kept strictly separate.
31. In 2017, with my new GP, I again raised my concerns about having HCV as a consequence of a blood transfusion in 1976 and the story of Anita Roddick. I asked about the possibility of infection with Hepatitis C, but again I was largely dismissed. I was told that the risk of contracting HCV through a blood transfusion at that time was very small. The GP did not offer a blood test for HCV.
32. Later in 2017, I had a routine blood test for Irritable Bowel Syndrome ("IBS") and a colonoscopy. I was seen by a GP I did not know, and she informed me that everything was fine with my tests other than a raised "mark" on my liver. The doctor told me that the mark was possibly a sign that I had just been fighting off an infection. She said that I should make an appointment to see her in six months to monitor it. Six months

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passed, I had been feeling mostly well, I was busy and knew the doctors' surgery was pressured with the 'flu epidemic of 2017/18. I didn't go back for the six month check.

33. Twelve months after the blood test that showed a raised liver marker, I had another blood test, which showed raised liver markers again. The doctor seemed surprised they were still raised.
34. Following this reaction, I mentioned my concerns about Hepatitis C to her. She responded saying that she did not like unanswered questions and that we should "follow this up". Subsequently, I had a blood test to see if I had HCV.
35. Around two or three weeks after I had the test, the doctor telephoned me and told me that I had Hepatitis C. This was early December 2018, over 42 years after I was first infected.

Information

36. I would rather have been told this news at a face-to-face appointment with the doctor. Nevertheless, she was very supportive when she gave me my diagnosis over the phone and was available to answer my questions when I called her the next day for more information. However, she was straight with me that she knew very little about HCV so could not give me all the answers I wanted.
37. In the light of her limited knowledge about HCV, my GP directed me to the Hepatitis C Trust. Samantha May, who runs the helpline, was very informative and was able to answer many of my questions about Hepatitis C.
38. I asked her about the risks of infection through blood left on surfaces and other such incidents, and she reassured me that it is not easy to transmit the virus in these manners. I also did a lot of my own research about the subject on the internet, so I felt confident enough to ask questions of people and find the answers that I needed.
39. I was also concerned about the risk that my family might have been infected over the years. The GP acknowledged there was a possibility, but the chances of infection were not high.

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40. After I was diagnosed, my GP sent an urgent referral to North Hampshire, Basingstoke, Hospital. When I attended my appointment on 21 December 2018, I found that I had been booked into the wrong department of the gastroenterology unit.
41. I attended the gastroenterology department as instructed, but the appointment had been booked in error with the team that did not deal with HCV. The "wrong teams" registrar was clear about not being an expert on HCV. Nevertheless, she answered as many of my questions as she could and arranged to transfer me to the Hep C consultant.
42. In order to save time, she organised blood tests and a liver scan so that when I saw the Hep C specialist all the essential information would be available. She also conducted a physical examination of my liver, noting she could not feel any hard edges. She raised concerns about my neuropathy and told me that, as no cause for had been identified, it might be related to the hepatitis.
43. It was then the 'wrong teams' registrar informed me that she did not think I would be eligible for treatment. She did not explicitly state the reasons for this, but implied that it was because the virus had not yet caused enough damage.
44. I interpreted her comment, made earlier in the consultation, that having had the infection for 43 years, something else was likely to get me first, as possibly referring to the fact that my age also raised questions that may affect my eligibility for treatment.
45. Hearing that I was probably not eligible for treatment really upset me. I felt very anxious, and for a brief moment, some days later, even considered suicide rather than face the possibility of HCV running its full course. It was very distressing to hear that I had this disease, and that treatment that could clear it was available but that it would probably be withheld from me.
46. I was told that my next appointment would not be until the end of March 2019. This was a long time to wait. I decided to research the disease and the treatment myself on the internet. Some of the research I found caused me even more anxiety, but it was my only way of accessing information whilst being made to wait a few months for my next appointment at the hospital. I had a lot of unanswered questions, and the internet was readily accessible.

47. The hospital arranged for me to have a follow-up appointment on 26th March 2019.

This was with another registrar. I pointed out that the consultation needed be with the specialist, as the initial appointment had been with the wrong team in the gastroenterology department. However, as the computer records showed I had already had an initial consultation, the consultant's secretary refused to make any changes. She explained that I would have to wait months if I wanted to see the specialist, as she was booked up months in advance.

48. The initial delay, then error on behalf of the hospital and then a further delay was too much for me. My GP agreed and wrote to the hospital requesting the appointment to be with the consultant, and for it to be brought forward if possible. As a result, although the date could not be changed, the HCV consultant wrote a personal letter to me and switched me over from her registrar's list to her own list for the March date.

49. When I finally saw the consultant, she was very reassuring and informative. Best of all, she offered treatment. The liver scan showed that the scarring on my liver was worse than they had expected. She also picked up on the peripheral neuropathy which she hoped might improve once I had been cleared of the virus.

Section 3. Other Infections

50. I do not believe that I have received any infection or infections other than HCV as a result of being given infected blood.

Section 4. Consent

51. I do not believe that I was ever treated or tested without my knowledge or consent. As far as I am aware, I have never been treated or tested for the purposes of research.

52. I have been asked to comment on whether I believe I have been treated or tested without being given adequate or full information. I do not recall signing my consent specifically for a blood transfusion, but as I have outlined above I have seen my medical records where I did consent to 'such further or alternative operative measures as may be found necessary...'

53. I am certain that I was not told of any risks associated with receiving a blood transfusion.

Section 5. Impact

Physical Effects

54. I feel that I have mostly been fortunate that my Hepatitis C infection progressed slowly and that I was not also infected with Hepatitis B and HIV. While I have been negatively impacted by it, GRO-B Treloar School and am aware that others who were treated with infected blood products/transfusions have often had far more challenging and devastating experiences.
55. Probably the earliest manifestation of the virus was a tendency to general fatigue, swollen ankles and significant bruising that was very slow to fade.
56. The main physical effect from HCV I have is neuropathy, which is a nerve disorder. I feel numbness and discomfort from my toes up to my knees. Sometimes, I am uncomfortable even when I am just lying down. I can no longer walk as much as I used to, and it has affected my balance. I believe this and my tendency to bruise easily is linked to the HCV.
57. I first became aware of developing neuropathy in my toes around the late 1990s. When I saw the GP about the discomfort he reassured me that it was mild and unlikely to spread further than my feet. However the neuropathy continued to creep past my ankles and I was referred to a consultant in 2009 to check for a possible cause of neurological damage. However, it appeared there was no explanation for the neuropathy. In August 2017 the neuropathy had reached my knees, so I once again broached the subject with a different GP.
58. It was during this appointment with the GP that I took the opportunity to question the possibility of whether the blood transfusion might have been contaminated with HCV. This was dismissed; I was told there was only the slightest possibility of contracting Hepatitis C from a blood transfusion. The GP did not make any connection between HCV and peripheral neuropathy (and I still did not know the possibility existed). However, the GP did refer me to a neurology consultant again and an appointment finally came through 10 months later in June 2018.

59. By this time, my driving licence had been withheld by the DVLA pending the outcome of a full medical report on the neuropathy. The consultant mostly reiterated the previous report in 2009, diagnosing peripheral neuropathy with no known cause and predicting, based on the progress of the neuropathy so far, that future deterioration would probably be slow. He did not ask any questions about my past medical history with reference to blood transfusions or make the connection between HCV and neuropathy.

60. However, the registrar and the Hep C consultant in the gastroenterology department at the North Hampshire Hospital, Basingstoke, both picked up on my neuropathy and the possibility that is linked to HCV. They have indicated that the neuropathy and other physical conditions might subsequently lessen after treatment of my HCV. Referring to the damage to my liver, the Hep C specialist nurse advised that there would hopefully be some recovery but that it would not be 100%.

Mental Effects of Infection

61. Since being diagnosed with HCV, I have been worrying about the people I may have unknowingly infected in the 42 intervening years between being infected and being diagnosed.

62. In particular, there was one woman who helped me clean up some of my blood after I knelt on a drawing pin and bled heavily. She would not have been wearing protective gloves. She was the first person I thought of after I was diagnosed, even though this incident happened thirty years ago. We are no longer in touch, so I am unable to trace her and warn her. I do not know whether she had any open wounds at the time. The thought is constantly on my mind that there may be somebody out there who I may have unknowingly infected – somebody who may not yet even know. That does play on my mind.

63. Since my first child, I have suffered intermittently from depression. While the first lot of postnatal depression was before I was infected with HCV, I believe the HCV has exacerbated my fatigue and contributed negatively to my depression over time. While I do not know if there is a conclusive link between HCV and depression, I believe there may be one.

Treatment

64. At the end of my consultation, the Hep C consultant proposed treatment. She indicated that it would need the approval of the Board in Southampton which would decide on the type of antiviral drug appropriate for me. She said that there would not be a problem with the approval, but there might be a short wait as a limited number of patients were treated each month. Meanwhile, the Hep C specialist nurse was in touch with me and gave me a full account of what to expect of the treatment and how it should be administered.
65. In the end, the wait was only two months. I started my treatment for HCV on 23rd May 2019. I was placed on an eight-week course of Maviret, taking three tablets at the same time every day after food. Before the treatment started, the nurse warned me of the potential side effects – headaches, tiredness and nausea.
66. I found I tolerated Maviret well. No headaches. Sometimes tiredness, other days feeling energised. I did sometimes have abdominal discomfort or pain.
67. I am grateful that I have now received the HCV treatment and am hopeful that the twelve week blood test at the end of October will indicate viral clearance. I will then have further tests at the 24 and 48 week stage which will hopefully confirm I am clear.
68. Given the fact that the NHS had actually given me this infection in the first place, I feel it should not have been so difficult for me to find the pathway to access the medication, nor should it have taken over forty years for me to be diagnosed when I had raised concerns with GPs much earlier. If the GPs had not dismissed my concerns out of hand, I believe that my infection would have been detected at an earlier stage.
69. Of course, this would have taken me down the route of a "catch 22" situation. Before the new DAA drugs had been developed, the earlier treatments were less effective, longer in duration and inflicted unpleasant side effects. Then, when the new drugs initially became available, because of the expense involved, treatment was limited to those most seriously ill. Knowing there was a cure that was being withheld would have been intolerably stressful to endure – as I experienced during the three-month gap between my seeing the registrar of the non Hep C gastrointestinal team and the Hep C specialist.

70. I also struggled with the breakdown of communication at Basingstoke Hospital. After the initial unsuccessful consultation in December 2018, I was then sent a follow-up appointment with the same wrong department early in 2019. On cancelling this, I had to contact the secretary of the Hep C consultant to confirm whether there had been a referral for an appointment with the Hep C specialist. On checking this, the secretary told me it was still waiting to be processed and I would be sent another appointment in time. That appointment communication never arrived. On phoning again after some weeks' wait, I was able to confirm an appointment date but was told this was with the Hep C registrar as it was a "follow-up" appointment. When I tried to explain that I had not yet seen the Hep C consultant because of the previous error, I was told I would have to wait months to have a new appointment with the specialist as her time was booked so far ahead. It took a letter from my GP to the consultant to sort the muddle.
71. Repeatedly being referred to the wrong departments and doctors just added unnecessary stress to an already stressful situation. All appointment reminders from the hospital include the warning that a missed consultation costs the NHS £160. Muddles initiated by the bookings centre are simply exacerbating financial wastage. It wastes money that could be directed into the cost of treatment.
72. Being told, initially, that after carrying the disease for so long, the damage to my body was not severe enough to be treated, was very distressing. At that time, I could not see the point of carrying on if I could not be treated. I should not have been put through this emotional distress just to get treatment for a nasty disease caused by the NHS in the first place.

Impact on other medical or dental care

73. I have been asked whether my infection with HCV has impacted my medical or dental treatment for other conditions.
74. Fortunately, I have experienced no negative impact in this area. My dentist took the news very calmly and didn't make any issue of it. He is aware that my gums have a tendency to bleed, which could also be connected to HCV, but it has not affected my ability to get treatment. He has also diagnosed oral lichen planus. It appears that infection with Hep C increases susceptibility to this condition.

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Private, Family and Social life

75. My family have all been very supportive of me during this time. I told my husband everything as soon as I found out, and he has supported me throughout. I worried about whether I might have passed the HCV on to him, but according to his medical records, GRO-C
76. Even with a supportive family I did I feel like a biohazard at home. I decided to go out and buy some gloves for my husband, so that he would be protected if I cut myself and he had to clean up.
77. I did not tell my adult children until a few months after my diagnosis, as I wanted to wait for the right time to tell them. My daughter was quite angry about what had happened to me, whereas my son was more gently concerned. Naturally, they were both also concerned about whether they might have contracted HCV from me and whether their families might also be infected.
78. Apart from my family, I have not told many others about my infection. I told one close friend early on, and she was very supportive. However, I did not talk about it more generally until shortly before I was due to start my treatment.
79. I think my reluctance to share was due to the stigma that surrounds the disease, even though I have never experienced the stigma personally and have not encountered prejudice because of it.
80. Generally, the main reaction of others has been ignorance. I have been particularly shocked at the ignorance I have encountered within the medical profession. It is as if specialisation has eliminated awareness of the importance of divergent thinking required to solve "unanswered questions".
81. From what I have read of the experience of others in my position, there is still a lot of ignorance about HCV and the ways that it can be spread. I strongly believe that this ignorance and prejudice should be dispelled.
82. To my mind, the systemic ignorance within the medical profession is exasperating and inexcusable. Because Hep C is mainly associated with drug use, there seems to be a lack of willingness to consider that patients other than addicts can be afflicted. The

reluctance within the NHS to accept responsibility for the consequences of using contaminated blood has been similarly frustrating. This has resulted in ignorance in the general population and means that others like me, who were innocently affected through contaminated blood, may not realise they are infected and could be suffering from and spreading the virus.

Work-related and financial effects

83. It is hard to know how much my early retirement can be attributed to HCV. I retired early as I was finding it difficult to cope with the stress and pressure on teachers following the National Curriculum overhaul to the education system and repeated changes and new initiatives introduced quickly. I do not know whether I would have been able to cope with the demands of the Department of Education and Ofsted more effectively if I had not had Hepatitis C. I think I did react more negatively to the changes than many of the school staff, although I was older. As such, I decided to take early retirement after I learned the local education authority had a contingency plan to facilitate this.

84. My early retirement has of course negatively impacted the amount of money I am entitled to in my teachers' pension, which is less than it would have been if I had taught up to the state retirement age. This is significant as I have also suffered a reduction of 40% in my expected state pension since the introduction of the changes to the value of the married woman's stamp.

85. I have been asked whether my infection with HCV has affected my ability to obtain insurance. I do not know because I have not tried to obtain it since being diagnosed with Hepatitis C.

Section 6. Treatment/Care/Support

86. As mentioned above, I was initially informed that I was not eligible to receive the treatment for HCV. Fortunately this was later changed so that I have now received treatment. Nevertheless, it was greatly distressing to first be told that I was not eligible for treatment, having carried the disease for so long.

87. I have never received any counselling or psychological support in relation to my Hepatitis C positive diagnosis. It was never made available to me. Fortunately, my GP

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directed me to the Hepatitis C Trust and Samantha May, Head of Support Services at the Trust replied to my email. She encouraged me to call her and she filled that counselling gap. I struggled when I did not have anyone I could turn to for answers to my questions, but thankfully the Hepatitis C Trust has been amazing in that respect. Samantha May was my lifeline in terms of the support and information she gave me, and the Trust website is also very informative.

88. I have discussed with the Inquiry investigator the existence of 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

89. Before my claim in March 2019, I had never received any compensation for being infected with HCV. I was not aware that I could seek compensation until I spoke to Samantha May at the Hepatitis C Trust. She encouraged me to go through with an application to the England Infected Blood Support Scheme ("EIBSS"), which I eventually submitted on 28th March 2019. My consultant also advised me of the financial ex gratia payment available and has been proactive in supporting my application. Therefore, my experience of the application procedure has been quite good.
90. The consultant wrote to the EIBSS to support my application and confirmed that she believes I contracted HCV through a contaminated blood transfusion. She has also provided evidence of chronic infection.
91. I initially had reservations about applying to the EIBSS for compensation, as I did not want to take money away from the NHS. However, I have since learned that the EIBSS is funded separately from the NHS. I have now had my application for ex gratia payments approved and the lump sum and the monthly payments are being paid into my bank account.
92. Since I first made my application I understand that the unfair discrepancy between payments of different amounts from EIBSS depending on where you live has been adjusted. I am grateful for the fact that I have been approved for ex gratia payments, as I have carried this disease in my body for over 42 years.

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93. I hope that one benefit of the Inquiry will be that the government/NHS acknowledges that the ex gratia payments should be considered compensation. The issue of the NHS using infected blood when safety had already been questioned requires full acceptance of responsibility for the reduced quality of life of affected individuals, and tragically for some, the loss of life.

Section 8. Other Issues

94. I want to see more awareness, information and accuracy of communication within the NHS as a result of this Inquiry. I believe that all doctors need to be better trained to be alert to indications of HCV – particularly when patients have received blood transfusions or blood products prior to the early 1990s.
95. I understand the pressure that is put on GPs to keep to routine ten-minute appointments, but I feel that they still need to ask questions if it appears that there is no obvious cause for a symptom. Bodies do not just go wrong with no cause. If more of my GPs had asked questions, I believe that I would have been diagnosed earlier.
96. I also believe that I should possibly have been traced when the NHS did the HCV lookback exercise. My NHS number has not changed – my records were still in storage. The batch numbers for the blood were included in the copies I received, so I question why I was not traced, contacted and advised to get tested.
97. I believe there needs to be more general education about Hepatitis C. In my experience, HCV is not really profiled, especially in comparison to Hepatitis A and Hepatitis B. I did not know much about it until Anita and Samantha Roddick campaigned about it publicly. I believe they may have saved my life, because their campaign led me to ask questions about my health.
98. There appears to be an overemphasis on the drug-related side of this disease, whereas information on the issue of contaminated blood is not brought to public attention. Is this because the NHS/government want the infected blood issue kept quiet? I believe this whole infected blood scandal needs to be out in the open completely because people need to be made aware of what HCV is, what it can do, and the possibility of infection after receiving blood products during the time when contamination was a real risk.

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99. I believe the government/NHS have failed and need to take responsibility for HCV and other infections inflicted on people through contaminated blood. The health system spends significant amounts of money on cancer treatment to cure or prolong life. I wonder why Hepatitis C – which has a very high cure rate with the new drugs – is not financed similarly?

100. I believe there needs to be a government-led nationwide public health awareness campaign. If the public are not aware of the disease, it cannot be eliminated.

Statement of Truth

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

Signed

GRO-B

Dated 25.08.2019

ANONYMOUS