

ANONYMOUS

Witness Name:

Statement No.: WITN0718001

Dated: 10 January 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 November 2018.

I, will say as follows: -

1. Introduction

1. My name is . For my own reasons I wish for my identity to remain anonymous.
2. My date of birth and address are known to the Inquiry. I am a retired police officer and a former sufferer of Hepatitis C. I intend to speak about my infection of Hepatitis C via a blood transfusion in 1988. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it has had on me.
3. I joined Brighton Borough Police in 1967 just before the amalgamation of the Sussex Forces into the Sussex Constabulary, which later became Sussex Police. After working as a uniform officer, I joined the detective

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ranks in 1975 and was promoted to sergeant in 1986. On retirement in 1998, I re-joined as a member of the support staff and worked mainly in the Information Security area retiring from the force as the **GRO-B** **GRO-B** in 2013 at the age of 66.

4. I was lucky that during most of my service I was a member of a group private health scheme.

2. How Infected

5. In 1986 I was diagnosed with ulcerated colitis, this is where your body starts to treat the lining of your colon as an alien matter and rejects it. It is very painful and unpleasant. This causes the colon to bleed and ulcerate. I lost a stone and a half in six weeks.
6. I went to see a private consultant and was treated with steroids and salazopyrin. It's a very obnoxious drug that makes your urine go bright yellow. It cannot cure colitis, it just manages it.
7. By 1988 the whole of my colon lining had basically gone and I was living on steroids. My doctor told me that I had lost the battle with colitis and I was referred to a surgeon called Mr Andrew Clarke.
8. The original idea was for me to have a pan colectomy and a stoma created, this means that the colon is removed and a stoma is fitted on the outside of the abdomen. The stoma is created by the end of the small intestine and feeds your waste products into a bag which has to be emptied and changed on a regular basis.
9. Luckily my surgeon was involved in trials of a new procedure called a Parkes pouch, which if successful, eliminates the requirement for a permanent stoma and replaces this with an internal pouch.
10. I obviously opted for this course and had three operations. I went off sick from work and it was unclear whether I would return to work after the operation.
11. My physical condition at this time was very poor, due to weight loss and the high doses of steroids that were required to stabilise my condition.
12. My first operation was on 19 June 1988. It involved the removal of my colon and large intestine, the creation of a stoma so I still had a system

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working and the restructuring of my rectum. This took nine and a half hours.

13. I was discharged and went home and worked on getting fit and healthy again because I was still very ill. My surgeon told me that sewing me back up again was like working with wet blotting paper.
14. My second operation was on 24 October 1988. This operation was to build the Parkes pouch from a portion of the small intestine. I had to have an artery redirected to make sure the pouch had a sufficient blood supply to work. I still had a stoma while the pouch was healing.
15. I had to have a lot of tests to make sure the pouch was working to ensure that it could take the pressure and work properly once the stoma was removed. Both the first and second operations were extremely long and during these procedures I received a number of blood transfusions.
16. After a number of stress tests on the pouch, I had the last operation on 25 November 1988 to disconnect and remove the stoma and connect the pouch.
17. All these operations took place in the Nuffield Hospital, New Church Road, Hove. This hospital has now closed down.
18. I was very focused on recovering from the operations I'd had and was busy trying to work out how to live with the pouch on a day to day basis and to make sure it didn't affect me at work. I didn't want it to affect my job and career too badly even though I had a funny system inside me.
19. In 1999, Mr Andrew Clarke, my consultant who had overseen my three operations, contacted me, he was retiring and he wanted to ensure that all was okay before he did. I made an appointment with him and during a series of tests a blood sample was taken from me. As a result of this blood test it was subsequently discovered that I had contracted Hepatitis C virus (Genotype 1).
20. The most likely cause of this infection is considered to be the blood transfusions I had been given during my first two operations in 1988.
21. At the time I didn't think anything of the blood test, I had regular blood tests to make sure everything was working post-operatively because the Parkes pouch is different to a stoma. I was used to tests to make sure the pouch was working correctly.

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22. After I had my blood test I think Mr Clarke wrote to me to ask if I could come in to see him. Once I was with him he told me that the blood test had revealed I had Hepatitis C. We spoke about what this meant for a while and he told me he knew a consultant, Dr Ireland, who was a hepatologist at Royal County Sussex Hospital.
23. I was surprised and shocked when I was told I had Hepatitis C. I tried to work out how I'd been infected, at first I thought it might have been through my work but I didn't deal with the usual people the drug squad normally came into contact with so I was very confused about how I'd contracted it.
24. I saw Dr Ireland very quickly and he said that the results of the blood test indicated I also had liver damage.
25. Late in 1999 I had a liver biopsy which showed that on top of Hepatitis C, I had cirrhosis and fibrosis of the liver. I received these results in 2000.
26. I wasn't panicked at these results but I remember thinking what do I do now? I was aware that all the time Hepatitis C was in my system it was damaging me.
27. The situation was aggravated at this time as there was no cure for Hepatitis C or really even an effective treatment to reduce the damage being created. I saw two different consultants, both privately, but neither was able to offer any way forward.
28. As I was used to fighting my previous issue (ulcerated colitis) I found this very difficult. I have always worked in a culture where you needed self-reliance and discipline but your support network was always banter, black humour and camaraderie. Now I felt like I couldn't share what I was going through.

3. Other Infections

29. No other infections have been discovered, when I was policing I was tested for Hepatitis B. I have never been tested for any other form of Hepatitis at a hospital.
30. I don't remember being spoken to about testing for HIV and I don't know whether I have ever been tested.

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4. Consent

31. I was not told about my blood being tested for Hepatitis C, I do not know what prompted Mr Andrew Clarke to test my blood for it and I was not told about the risks of receiving a blood transfusion when I was having my operations 1988.

5. Impact

32. As far as I was concerned, Hepatitis C was an illness associated with a bad lifestyle including drugs and unprotected sex. This was not an illness that invoked sympathy or, in the culture of that time, one that you discussed with your work colleagues. I was advised early on to ensure that even when dealing with the medical profession, I pointed out to them and made sure they understood that I had contracted the illness through a blood transfusion and not a life style choice. This made sharing my situation with colleagues and my family either impossible or at best extremely embarrassing. Luckily it was not necessary to reveal my condition at this stage of my career as a Police Officer. In 1990/91 I had taken over the Holmes Unit, a team of officers who organise and run the Major Incident Rooms across the force, including the computer systems. This meant that under normal circumstances I had limited contact with members of the public. I was able to perform my duties without any problems.

33. One vivid memory is the embarrassment of explaining my condition to my two nieces who both had very young children at the time. I felt very uneasy about the possibility of contaminating either them or their children and decided that I should explain my situation to them and let them decide.

34. I arranged to meet with both of them and explained the situation and my knowledge at the time. I was amazingly impressed that they seemed to take the whole issue on board and then both stated that they wanted me involved in the future of their children and that I could continue to visit and see them. Although that was a lovely outcome for me, the embarrassment and stress of that conversation will live with me forever.

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35. I told my friends after I retired because I can no longer drink when I'm out with them, despite my fears they accepted my news and said "so what, you're still you".
36. I had to tell my wife as soon as our relationship started, I told her how careful we had to be, especially if I had a cut anywhere on my body. I explained to her that sometimes I might not be able to kiss her. I told her that the virus could only be transmitted through blood so she couldn't get it from any other bodily fluids but I stressed how careful we had to be.
37. Telling my friends and family was definitely one of the hardest parts.
38. There wasn't a half way mark, I either told everyone or no one, so I carried out my own risk assessment and tried to keep it as private as possible.
39. The worst effect is the number of years I have had to go through living with and knowing I had the infection. It's the part that plays most on my mind and the effects of the cirrhosis means that my life will be shortened anyway.
40. I'm living with the thought that I could easily get cancer in my liver and I've seen friends die and it plays on my mind.
41. When I moved to my current house and registered at my local dentist I had to fill out a form and state that I had Hepatitis C. I then informed them when I no longer had it but my dentists didn't seem that bothered when I did.
42. My wife was told that she could no longer give blood because of her marriage to me. She has never been tested for Hepatitis C.
43. I have for most years had private health insurance through the police force group schemes and had to disclose my illness but I never had much problem with it. I have yearly travel insurance, which is an annual payment, so I was able to go away even when I was ill.
44. I went to Paris, the Maldives and Germany when I was being treated and had to take medicines and syringes with me on these trips. I needed a letter from my doctor to explain why I was taking such things abroad.
45. I had a fairly successful career despite the brain fog. Even when I was GRO-B which was a force-wide role I was still able to do my job.

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46. I am fully retired now. That said, I am the GRO-B for the resident association of the apartments we now live in, a job that I share with my wife. Sometimes I find this challenging when I'm having a bad day.
47. My wife and I are very angry and frustrated. We don't know how much time I have left and it's something we have to live with every day.

6. Treatment/Care/Support

48. After Mr Andrew Clarke retired in 2000 I went to GRO-B in Worthing and met Dr Kerry Thompson, who became my consultant from 2000 until she retired last year.
49. She thought it was best to send me to Royal Free Hospital in London as a professor there was actively conducting various trials of treatments to cure hepatitis at this time. I was told that my best chance of being cured was to be on one of the trials.
50. In 2001 I was considered suitable for a clinical trial of pegulated Interferon and Ribavirin. This consisted of daily tablets and a self-administered injection once a week.
51. However after seven months, tests showed no improvement in the viral load and the trial ended.
52. I travelled to London from the south coast to visit the hospital numerous times during this period for tests and consultations. To visit the Royal Free from my home for both the clinical trial and the on-going consultation took a full day and I therefore had to use either a rest day, time off or an annual leave day, I could not go sick. This was the hardest thing because I hadn't told my job what was wrong with me. It was always a very long day and I didn't fully appreciate that I wasn't very well.
53. I had a number of side effects to the Ribavirin. It would take me approximately three days to get back to fully functional after the injections. I was very tired and looking back now this tiredness was accompanied by depression. I had aches and pains like a mild dose of flu. If I had brain fog I didn't clock it at the time, I just thought I didn't understand.
54. I wasn't put on another drug trial at Royal Free, but I went for six-monthly visits. Those clinics in the big hospitals are like a big sausage factory and I

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- saw a different person every time I went. They always just referred to my medical notes and there was no consistency.
55. I got a blood test done at my local doctors every time I was going to Royal Free and I took the blood sample with me. I had an endoscopy every year at the Worthing Hospital as well.
56. Having visited the Royal Free Hospital at intervals varying from every six months to once a year, in 2011 it was decided that this was a waste of time and from then on I only saw my local consultant.
57. I had regular consultations and general check ups with Dr Thompson until 2018, when she retired.
58. In early 2013, I had joined several Hepatitis C and Infected Blood groups on Facebook. I read something online about a hospital in Brighton treating Hepatitis C, particularly non-responders to Interferon. My consultant referred to me to the clinic at the Royal Sussex County Hospital in Brighton run by a Dr. J. Tibble.
59. After a consultation and tests he agreed to treat me. He spoke to me at length and said he thought I was an ideal candidate for this new treatment. He told me there were other options that would be available over the next few years. He also said if it was him, he wouldn't go on the clinical trial that was immediately available to me because I was reasonably healthy. He said something new might come along in the future.
60. I didn't want to wait; my reasoning was that I was getting older and progressively more unwell. I didn't know how expensive new treatments would be and if the government would fund them. I therefore chose to go for the immediate treatment.
61. My treatment started in March 2014 ending in February 2015. It consisted of: Incivo (375mg) (Telaprevir) and Copegus (200mg) (Ribavirin) I had to take three tablets of each twice a day. I also had Pegasus (180mg) (peginterferon Alfa-2a), which was injected weekly.
62. The side effects of the treatment were severe, 2014 was an absolutely horrendous year. I lost weight again, I was very, very ill. The treatment initially started with three drugs and then after a few months dropped to two. I was on a slow downward spiral as the toxicity of the drugs tried to kill the Hepatitis C. I could walk less and less and I slowly drained away.

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63. My muscles were failing and when my wife and I took a trip to Paris. I could barely walk down to the nearby restaurant.
64. My wife and I had set 2014 up as a bucket list year just in case things got really bad. We did things we could look back on in the future. We went to the Maldives, just in case we never got to go again. Luckily when we went, our accommodation was the closest to the restaurant and resort area. It was 150 metres of sandy beach to the restaurant but sometimes it felt like a mile.
65. We didn't want to say to people what was wrong so when they asked I just said I was on medication. People assumed I had cancer. The manager of the hotel in the Maldives offered to wheel me around in a big wheelbarrow, as they didn't have wheelchairs. I found this idea quite funny.
66. When I was with the police the method of counselling in my day was having a pint with my mates in the evening after the job but we never shared things that were personal. It wasn't the sort of thing that came up in conversation.
67. Hepatitis C was and is a disgusting, horrible disease to everyone. The people that had it were the dregs of society but I wasn't like that and I didn't want people thinking I had slipped up.
68. I hid the fact that I had it in a box in a cupboard in the back of my brain and I didn't want to let it out. That was my coping strategy.
69. During my careers I worked on, dealt with and saw lots of horrendous things. I had developed a coping strategy of placing bad things in a box as described above. But during the Hepatitis C treatment and the side effects of drugs I was on let some demons out. This was very difficult to cope with and added to the depression.
70. I used to think that I didn't believe in depression, but when I was going through this treatment I had a lot of depression.
71. The nurses were brilliant and explained all the way through what it was going to be like. But my wife and I didn't appreciate how bad it was going to be.
72. To make some of the drugs effective I had to eat 30% more fat in my diet but the whole problem had stemmed from my stomach so I struggled. It's

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amazing how some foods, cream cakes for example can become so unappealing.

73. The nurses suggested I wrote a daily blog, which I did for a while, but I couldn't keep it up for long as it just reinforced to me how bad I was feeling.
74. Throughout my career I had never understood what it meant and felt like to have depression. I have worked with people that had it and PTSD but it had never affected me. What I found in the treatment was that my ability to compartmentalise had gone. The things I had used to defend myself were being whittled away.
75. The nurses had told me that depression would be one of the side effects of the treatment. I had listened to them when they told me that and thought, "I can deal with that". Being told something and then finding that you are experiencing the symptoms are very different. The reality is not good.
76. My skin also itched as a result of the treatment; this is something that still affects me today and I have to take anti histamines on a daily basis.
77. Towards the end of the treatment in 2015 I had a final blood test and I received the results back about a month later. The results said there was no detectable indication of the Hepatitis C. This was checked and verified six months later. As far as I know I am now cured, however, I have learnt that the virus is very clever and it can hide in your system. I remain to this day clear which is a relief.
78. My wife has had to take the brunt of my depression, mood swings and general exhaustion that this treatment caused has supported me throughout. In praise of her I would say that without her I do not think I would have made it.
79. Fatigue seems to be a serious issue if you are infected with Hepatitis C. It is a feeling of complete exhaustion that can occur at any time. When I was a detective I became used to odd hours, long shifts and short breaks. It was possible to cope with all those. However a sudden feeling of total exhaustion was and is sadly still a very different issue.
80. The side effects I suffered from the treatment in 2014 come and go in cycles. I have shortness of breath my wife and I try to walk at least twice a day. When I'm good I can walk four-five miles without noticing but when

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I'm bad I can be out of breath by the time I've walked 100 yards. I experience tiredness but it's more like total exhaustion, like I have physically pushed my body too far so that it's had enough.

81. The cycle seems to last a couple of days, I can fight to work my way out of it but it takes effort.
82. Brain fog is a side effect that is difficult to comprehend and explain, it is as though your brain decides not to interpret data effectively. What should be a fairly simple task of absorbing facts and processing information becomes a mental battle. Some more complicated processing can require taking time out to enable your brain to kick back into gear and work effectively.
83. Although I no longer have a detectable viral count and am considered virus free, the damage that has already been done will remain with me for the rest of my life, along with the side effects I have described. I regularly suffer from extreme tiredness and constantly in the back of my mind are the reminder of the damage to my liver and the possible consequences of this.
84. This can and does make me depressed and emotional. Luckily I have a lovely wife who can lift me from the more depressive times and enable me to function. For this I will be forever grateful.
85. Now I only see my local consultant for my pouch and liver damage. My liver is still fully functioning although not as well as it should do and I have been told that it has shrunk and hardened like a cricket ball. I still have cirrhosis and fibrosis of the liver for which there is no treatment.
86. When my private consultant who I had been with since 2000 retired last year I was referred back to my local hospital. I have had one meeting with them and I am back in the 'sausage factory' now as another NHS patient.
87. I take blood pressure tablets; as I said earlier, I have to take Piriton which is anti-histamine daily to stop my skin itching. Sometimes I get marks on my skin where capillaries burst but these go away.
88. I have been advised to reduce my alcohol level to the bare minimum. Now I only have a very occasional drink and drink lemonade socially.

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7. Financial Assistance

89. I receive money from the Skipton Fund; I am at stage 2 due to my cirrhosis.
90. I have received a Christmas fuel bonus from the Macfarlane Fund in the past but this and my monthly payments from the Skipton Fund have all been combined together now.
91. My private consultant who looked after me from 2000 completed all the forms that were needed to on my behalf for me.
92. I can't remember how I came to know about the Skipton Fund. There was a form I needed to fill out and another one I had to send to my consultant to fill out and I think she then sent them off.
93. My recollection is that it wasn't a difficult thing. I filled out my form with my personal details and my consultant highlighted my condition and the level of damage to me.
94. At the time biopsies had been taken of my liver to show the level of damage. I remember the Skipton Fund wanted to know how I'd contracted Hepatitis C and they needed to know the damage to determine if I was at stage 1 or stage 2.
95. My acceptance to the Skipton Fund confirmed that I received the virus via a blood transfusion and not some other measure i.e. through my work. I don't have any tattoos and I didn't have any piercings prior to the operations I underwent.
96. A year after I applied to the Skipton Fund I received one large payment and the year after I received another, these added up to about £45,000.
97. I now receive monthly payments, which were £1,300 a month but have just gone up to £1,500. I also receive winter fuel payments. The payments I view as compensation for the NHS infecting me with the virus. Given the choice of no infection or the payments, it goes without saying that I would much rather have good health.

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8. Other Issues

98. Around the time of my diagnosis I had dealt with a case of 'administering a noxious substance', involving a husband and wife. At trial, the defendant pleaded guilty and was sentenced to imprisonment. (My recollection of the exact details of the case is a bit hazy).
99. Fairly obviously I linked this to my situation where I had been infected with a deadly disease that had not only caused serious issues with my health, but had damaged my liver to a point where my life would probably be shortened substantially. I am certain that the element of intent would not be proved, but knowledge of the risk and lack of action to prevent could be considered.
100. I haven't been able to get hold my medical records from 1988 and before because the Nuffield Hospital in Hove is no longer there and I have been told that all my records from 1988 and before have been destroyed.
101. I have tried to get all my records from all the hospitals and doctors I have seen over the years and I have been able to obtain some of them.
102. All I can find is medical descriptions in the documentation I do have. I don't have any information about my transfusions i.e. batch numbers and units I received.
103. I was never told by the Department of Health or the NHS that because I had a blood transfusion in 1988 I should go and get tested for certain diseases. To me this is very wrong as I received a blood transfusion when it was known that contaminated blood was a huge issue. Why didn't they tell me to undergo a test?
104. I don't know why Mr Andrew Clarke tested my blood for Hepatitis C in 1999. As I understand it that is a unique test. The blood test would have been done at the Nuffield Hospital where I had my operations. I expect he would have known about the risks and that I was given a potentially bad batch of blood.
105. Nothing was ever given to me to tell me about the risks but I believe they would have known when I had my operations that tainted blood was in circulation at hospitals.

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106. In 2000, after I was told about my infection, I went to see a solicitor in Brighton. They told me I could sue the hospital so I paid them £1000 to pursue this action. After a few weeks the solicitor came back to me and said that after some initial research they had found that it actually wasn't possible to sue because the hospitals/ doctors had crown immunity. The solicitor refunded me my money. This made me feel very angry and quite helpless as I was unable to hold anybody to account.
107. Even though for a number of years the basic facts of contaminated blood have been known, at no time has any effort been made to find those that have been affected by it. This is so wrong.
108. In my case it was a random blood test due to my surgeon retiring. It is very sad that without that I would have carried on for years without treatment, never knowing that I was infected. Sadly that could have resulted in me infecting somebody else thereby compounding the problem.
109. As to counselling and offers of treatment, I had nothing. No effort to provide additional support was made for me and unless I asked for it, nothing was provided. Luckily for me I was able to hold down jobs and I am now in receipt of two pensions. If not for that then through no fault of my own I would have been surviving on benefits.

Statement of Truth

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

Signed

GRO-B

Dated

18/1/19