

2 MAY 2019

GRO-C

Witness Name: Charles Kinnear

Statement No. WITN0945001

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHARLES KINNEAR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2 May 2019.

I, Charles Kinnear, will say as follows: -

Section 1. Introduction

1. My name is Charles Kinnear. My date of birth is GRO-C 1953 and my address is known to the Inquiry. I was an art investment consultant but had to retire because of ill health and currently live alone. I intend to speak about my infection with Hepatitis C and the impact it has had on myself and my family.
2. I confirm that I do not have legal representation and do not require anonymity, having had the provisions of the procedure explained to me. I would also like to add that events are sometime in the past and dates should be taken as approximations.

Section 2. How Infected

3. I woke up one day in early 2005 feeling really terrible with really bad aches and pains. It was something I had noticed gradually creeping up on me but I had always been fairly fit and just put it down to age and lifestyle. At the time I was reading an article by the owner of the Body Shop, Anita Roddick, who was writing about living with hepatitis C and I felt absolutely everything that she was describing.
4. I went to see my GP, Dr Singh, at the Paisley Road Health Centre in Leicester, and told him that I thought that I had HCV and wanted a test. Dr Singh told me I was being silly and that I didn't have it. As my condition didn't seem to be improving, I asked three times over a number of months and, on each occasion, he berated me said I didn't have the infection and refused to give me a test. By this time, I had developed a severe skin rash and my weight had dropped from sixteen stone to about nine and a half stone. He dismissed my concerns, saying the rash was probably due to my detergent and that I probably wasn't eating properly thus accounting for my weight loss.
5. I phoned the Hepatitis C Trust and spoke to Sam May, an incredible woman, and she said to go straight to the hospital and get a test.
6. I requested the blood test at Leicester Royal and three weeks later I got a call from a specialist nurse to say to go and see a Dr Grant. When I arrived, I was called through to see the specialist nurse in this nice room that looked like an aquarium. The specialist nurse said "do you want the good news or the bad news?" I said the good news and she said "you don't have HIV", the bad news is that you have HCV."
7. I was diagnosed with hepatitis C (genotype 1) on 10th August 2005.
8. The nurse sent me back to see Dr Grant, and he said to me, "Look, we've got all the results and you'll be starting treatment immediately." I asked

what treatment? He said it's a dirty drug and it was called Interferon. There was no information provided on what being infected would mean for me or anything about precautions to take nor about the side effects the treatment may have.

9. I have no real idea how I was infected. I can only suspect. Dr Grant asked me the usual questions at the time but I was never an intravenous drug user, and I have never been sexually promiscuous. I do have a couple of tattoos but I got them on the Kings Road in London in a professional setting. I had a large tattoo on my chest done about 35 years ago when my daughter was born. Again, it was all very hygienic though and professional.
10. Prior to being diagnosed with hepatitis C, I had numerous hospital visits. In 2002/2003 I was assaulted and badly beaten in Leicester, which resulted in 3 years of surgery. I was coming back to see my Mother in Leicester and saw a gang abusing and bullying a black woman with a baby. I intervened and put her in a taxi to get her away but as I tried to leave the gang attacked me and I was hospitalised. My jaw was broken in 2 places, my cheekbones were fractured. I lost most of my teeth and a number of my ribs were broken along with my right leg. I was also slashed all across my back with Stanley knives and sustained a stab wound in my neck.
11. As a result of this attack, I underwent numerous surgical procedures, but I am not sure if any of them required a major blood transfusion. It is highly possible that a transfusion was required as they did 3 or 4 operations just on my leg. The nose was a major operation. They had to remove a makeshift bridge that they had inserted for my nose. These operations happened in Leicester General, Leicester Royal, Queen's Nottingham, and Queen Elizabeth Birmingham. My career was seriously interrupted as a result of this attack and the subsequent surgeries and was then completely finished by the diagnosis of HCV.

12. Other than the above, I was involved in a serious accident in 1991, when my leg was crushed. I had to go to St Thomas' London. My leg was actually broken and I suffered nerve damage. A metal brace was inserted up into my leg and I was on crutches for a year. I don't recall having a blood transfusion but it is very possible I did due the extent of my injuries. From a time perspective, this would appear to be the most likely source.
13. I had joined the navy at 16 and did 4 years. I never had any medical issues nor was I hospitalised abroad during that time.
14. It was after the navy that I became an art investment consultant. All my life, I'd studied art. I had become interested in it as a young lad in Glasgow. My Auntie Lizzie took me to the museum and I saw Salvador Dali's St John on the Cross and since then it sparked my interest. I continued to study it and I met many interesting people who were really into art. I would travel all around the world locating and buying art for very rich people. I did this up until my career was ended following the attack in 2003.
15. Everything seemed to happen after my 40s. I'd been everywhere. I'd travelled the world and I'd never had any problems until then.
16. However, I do remember on one occasion, waking one morning when I was around the age of 28 so around 1980/81 and noticing my eyes were yellow. I went to the hospital and asked the doctor what it was and he said that I had jaundice and they put me in isolation and fitted me up with drips.
17. No doctors have ever offered me any explanation as to how they think I've been infected.

Section 3. Other Infections

18. I had a heart attack on 11th June 2018. I had cleared the HCV in 2015 and I was fit and healthy, so the cause of this came as a mystery to me. I believe that the treatment and general stress of dealing with the Hepatitis and getting myself on my feet after the HCV was a contributory factor in the heart attack.

19. Having completed the treatment and cleared the virus, I wanted to make people aware of HCV and had been trying to get people to help me tell my story. I have been trying to write a book called "A Cat Called Hitler". I had met Michael Winner at a comedy festival and we had become friendly. I had told him about my idea and he was going to help me to take it on the road. We were thinking of doing something like what Mel Brooks did with The Producers. Unfortunately, though, he passed away and so we were never able to do it.

20. As a result of the HCV I was a wheelchair user for many years. I always said that if I got out the wheel chair I was going to do a sky dive as a tribute to my Dad who was in the paras for 20 years. After I cleared the virus I had got myself really fit and so decided to do an assisted sky dive outside Nottingham. I told the guy at the company about my previous infection with hepatitis and he said that you're specifically prohibited from sky diving if you have had hepatitis. As a result, I signed a disclaimer to say that I was aware of this and was happy to go ahead and so I did my first assisted sky dive in 2017.

21. After I'd done it, I got in touch with the Hep C trust and spoke to Sam. I wanted to do a non-assisted sky dive as a means of promoting the Trust and raising awareness of the condition. Showing I can do it might also provide inspiration for others who are suffering. I know that there are men and women in this country who are really affected. I know if I hadn't found out I'd be dead. However horrific that treatment was, I persevered

and, in the end, I cleared it. I got in touch with a company to get them to make a parachute that said "no Hep C" on it.

22. However, I then found out that in the UK, you have to be under 55 to be allowed to do a first jump (non-assisted). The guy told me though that if I went to Spain, I could do the whole course. I took a three-thousand-pound loan from the bank and went to Madrid. In order to qualify to do the sky diving unassisted I had to complete sixteen jumps. However, I made the mistake of telling someone who was also staying at the sky diving centre that I had been a hepatitis sufferer and he in turn told the staff. I had only completed 3 of the 16 jumps at this time and they would not allow me to continue because of the virus.

23. After Michael Winner had died and I was preparing for my sky dive, I continued to try and write my book. I met a woman who worked in a charity shop where I had bought clothes and she came in to help me with the book. However, she took advantage of me and cleaned out my bank account. The bank knew it was her, but couldn't prove it. Apparently, she had hit another fifteen people. As a result, I lost the money the bank had loaned me. I am still paying it off now.

24. Even though I was fit and healthy, as I've mentioned, I think the effect of recovering from HCV, especially the treatment, coupled with the stress of losing the money and what happened with Michael Winner, all would have contributed to the heart attack. I definitely think the HCV was partly responsible for all of this.

25. I do not believe that I have contracted any other infections as a result of being given infected blood, apart from what I believed to be Hepatitis C.

Section 4. Consent

26. I always consented to all treatment. I consented to my hospital test that revealed the HCV. Knowing what I know now about the Interferon /

Ribavirin treatment, I wouldn't have done it. Doing it on your own with no support is awful. I'm sure it's different if you have people around you. I'd go to bed exhausted and wake up exhausted after 12/14 hours sleep. Woke myself up screaming, went into spasms. It was like God unplugged the power supply.

27. I don't think that I've been given anything experimental to be tested on and if I was then I wasn't aware of it.

28. I would say that I did not consent at any time to being given a blood transfusion and certainly don't recall any warnings about risk attached to these either before or after surgery. However, during both the procedures where I may have had a transfusion, it was likely they were necessary to repair the injuries I had suffered.

Section 5. Impact

29. My whole life was taken away from me. I went down from 16 and a half stone to basically a skeleton; I used to be a sportsman, but spent years in and out of a wheelchair. They moved me into a tower block in GRO-C 15 floors up and the elevator broke down for 3 weeks. I was critically ill at the time and then you'd have to walk down to the shops. At the time I probably weighed about 8 and a half stone. All those years in a wheelchair, the muscle loss and everything. I lost up to 10 stone in weight. I looked like I was out of Auschwitz. Then, around 10 years ago my mother died, my dad went to pieces, and my brothers walked away leaving me in a wheelchair on my own.

30. After I was diagnosed with HCV, I went to see my GP for regular blood tests and monitoring. In 2012, an MRI scan showed that I had a 1mm lesion in my liver (possibly larger). I was diagnosed with cirrhosis of the liver in 2014 and was referred to Queen Elizabeth Hospital in Birmingham where I was treated by Dr Shah.

31. This was after my first set of treatment with Interferon and Ribavirin in 2007, which had been unsuccessful. I was classed as a Non-Responder in my records. In the Queen Elizabeth hospital, I had a beautiful room with a private shower. The whole nine yards. However, it was the terminal ward. People were dying every day. The doctors had carried out blood tests and a biopsy and they said everything suggested that I had liver cancer, but needed to do a proper examination to confirm it. They said "we need to take a rod of radiation and go into you. It's a serious operation. It will last about 2 and a half hours. If we touch any of your organs on the way in, the only way you are leaving this table is dead."
32. The operation was a success and they were able to conclude that I didn't have liver cancer. I was actually on the transplant waiting list at the time that they did the radiation therapy but I didn't require it in the end. I am aware that currently only about a quarter of my liver is fully functioning.
33. I had started Interferon and Ribavirin treatment on 26th March 2007 and stopped treatment on 18th September 2007. I had the first Interferon injection in my stomach at the hospital and they showed me how to do it at home. The Ribavirin was in tablet form.
34. I went back to the house and then four hours later, it was like getting hit by a truck. I wouldn't wish it on the devil himself. I was taking Ribavirin tablets four times a day and Interferon injections twice a week. I didn't sleep for 185 hours. I tried to document the side effects on my mobile phone. I went to my GP and said you have to knock me out. I'm going to have a heart attack. I can't sleep. Again, he simply ignored my concerns and I got no help. I didn't go back to Dr Grant and the people at the hospital as I was worried they would stop the treatment.
35. I did 48 weeks of treatment and a couple of weeks before the end of the course Dr Grant told me to double the dose, and within days I was urinating blood and had to ring the hospital. In my opinion, the increased dose made me worse. It resulted in all my hair falling out. Every time I combed it, it came out in clumps.

36. I had 20:20 vision prior to treatment. They checked it before my treatment started. Within months of being on the treatment, I was blind. Not fully blind, but my sight was badly impaired. Couldn't see anything beyond a metre. The technician who checked my eyes at Leicester Royall couldn't believe it. He said to me most people's eyes do deteriorate, but yours have just fallen apart! I also lost all of my teeth or I should say, what was left after the earlier attack.

37. When the Interferon/Ribavirin treatment ended, I was in such a bad way that I ended up hospitalised and on morphine in Leicester Royal hospital for 2 weeks. They called in a Professor of Pain from the Macfarlane Trust, Dr Black, and he assessed me. Afterwards, he said "I want you to give this man this dosage of morphine immediately." They then wheeled me in to see Dr Grant, Dr Black, and the nurse. There were other doctors there. Dr Black said "have you any idea what it happening to you Mr Kinnear?" I said, "I'm dying" and he said "yes, you are Mr Kinnear. We have done everything medically we can do." I said "how long have I got?" and he said "You have about 3 months". I said that if I was going to die I was going to die at home, and so I discharged myself and went home.

38. I knew my own body and it was disintegrating. I was filling up cups with blood. My wheelchair use started in 2008 during this treatment, whilst I was living in Leicester. When I wasn't using the wheelchair, I was using crutches, walking sticks or mobility scooters. I had regular appointments with the physio and they had to teach me how to walk again as there had been so much muscle wastage. It looked like I was drunk every time I was trying to walk. Dr Grant had warned me that there would be some muscle wastage as a result of the HCV as it feeds off your body.

39. When I was in Queen Elizabeth Hospital in Birmingham, I met a lot of injured soldiers who were in the same ward as me. Through them I found out about the National Association for Bikers with a Disability who are a charity set up by bikers with a disability. Where I now lived was on a fairly steep hill which I couldn't negotiate in a wheel chair. I managed to obtain

a small motor bike from them which meant I could get up the hill. It helped me get my confidence back along with the walking which I was now doing on a regular basis to rebuild my leg muscles.

40. Another debilitating after effect of the treatment was that I couldn't remember things like dates, times, people's names. It was like being in a constant brain fog. Once, I was washing a window for five hours, just staring into space. I completely lost all sense of time and surroundings.

41. I was in so much pain. They gave me a repeat prescription for morphine after I discharged myself. I had been on so much in the hospital that when I left I was drinking 2 bottles of Oramorph a day. I did try to do it without morphine originally but the Professor of Pain said that I wouldn't be able to function without something for the pain. I was on a rolling prescription for morphine up until I had the Harvoni treatment in 2015 so eight years. When I cleared the HCV, I took bags of it back to the chemist and told them "I don't need it anymore".

42. I think that I got the treatment that was available at the time and nothing was held back from me. The Interferon/Ribavirin didn't work on me and there was nothing else available as far as I know until I had the Harvoni treatment in 2015.

43. I have been refused dental treatment in Leicester when they found out that I had HCV. It was in Belgrave Gate at a private dental practice. One of the first questions they asked was if I had HCV. Same thing happened in Nottingham, I was asked but I said I had cleared it, and he was very good about it.

44. I have had some problems with getting treatment at GPs as well when they found out I had HCV. I recall on one occasion when I was ill I went to my local surgery and the receptionist took one look at me and said "Mr Kinnear, just sit down, as I better call you an ambulance." I said I had an appointment with Dr Singh so I went in to see him to get his opinion but he wasn't interested in fact, he fell asleep! I waited a good

few minutes before shaking him to wake him up. He refused to treat me properly when I told him that I had HCV. So, I changed GPs.

45. I had the same thing in the Job Centre. The lady jumped back after I told her that I had HCV when I went to shake her hand. I suppose many people don't understand.

46. In Leicester, I was a regular church goer. When the community found out that I was infected, everyone that used to sit near me moved back about 3 rows from where I was sitting. It was embarrassing and belittling for me but a poor attitude from supposed Christian people.

47. When I told my brothers in 2005 that I had HCV, I never saw them again. One of my brothers is an ex-policeman. His wife was a top-grade nurse, and even they said never come to my house again. My other brother came over initially GRO-C so I got him some literature. But he was supposed to help me a few days later with something and did not turn up and I haven't seen him since. I've tried to call but nothing. I told my Mum and Dad and they were fine with it, but they are both dead now. I still have no contact with them.

48. I also lost all of my friends as a result of it. Well actually, I still have a few friends but they live in London so I don't really see them.

49. My family in Scotland have been more supportive. My sister just got a BEM from the queen for raising millions for charity. She has been supportive as have the uncles and aunties and cousins. I've had more support from them than I've had from my brothers.

50. I was married with a daughter when I was diagnosed. I told my wife and she didn't want me in the same house as a result of the Hepatitis C so I had to move out. She saw me during the treatment and witnessed some of the side effects and she just couldn't deal with it. She is Muslim and had a problem with me having the virus as she thought it was dirty and I

was unclean. Unfortunately, I think too many people, through ignorance and a lack of information, associate the infection with HIV. Shortly after, she filed for divorce. GRO-C

51. This is common in the Asian community. I went to go and talk to people about it to try and dispel some of the myths and was lucky to get out of people's houses sometimes. I saw a documentary about a woman who'd been infected in Pakistan and her community had turned on her. So, I knew some Asians in Leicester and went to share some literature with them, but the husbands would chase me out. In Leicester a husband chopped his wife's head off when she told him she had HCV.

52. Part of getting the message out was through discussions with Sam and the Hep C trust. I had cards printed and leaflets to try and spread the message and help other people. I never wanted any other human being to experience what I had. I wouldn't wish it on anyone in the world. The impact on your quality of life is horrendous. It affected everything, my brothers, my daughters (my other daughter moved to Japan when she was 18 months with her mother, my first wife and I haven't seen her since) and my wife.

53. When I was told I had HCV, they asked me if I had any children and I said that I had a daughter and they told me that she should have a test.

GRO-C I haven't heard from her since apart from to send me a text to say "You weren't there for me, so I don't need you now." She has two kids of her own so I have lost out on my grandchildren as well. Now that I am recovered, I am trying to make contact again as she lives in Leicester and I can only hope. I know it must have been difficult for her at the time but more is understood now.

54. On the social side, I was a regular drinker, but the minute that they told me I had hepatitis I didn't touch it for 10 years, then was a light drinker for a bit, but now I don't drink alcohol at all.

55. I had no social life or quality of life. I was living off about £40 a week. I was earning £10,000 per day when I was at my peak in about 1993. I was on commission so this wasn't every day, but I was doing well. I had to spend some of the money to set up and try and find these paintings but I was doing well. I was paying emergency taxes. After the attack, I was off work, but it was likely I could have gone back after recovering. However, when I found out about the HCV that was it.

56. All I wanted to do was also buy my parents a bungalow in Ayr and provide a good lifestyle for my wife and children but then I lost everything including the opportunity to do any of that.

57. The last holiday I had was 1993. Nobody would insure me. I phoned up every insurance company in Britain looking for health insurance. Sun Life were the only guys who offered but they wanted £250 a week.

Section 6. Treatment/Care/Support

58. I was never offered any psychological help or counselling in all the time I had HCV and was receiving treatment for the virus or any of its related illnesses.

59. Throughout all of this I have stayed in touch with the Hep C Trust to find out about new treatments in case there was anything suitable. It was through the Trust that I found out about the Harvoni treatment. I went to Queens in Nottingham in 2015 and asked for the treatment. The medication was prescribed for me within weeks and I cleared the virus. It was I believe a six week course of tablets and even though I know my liver is damaged, I am still alive as a result of it. I do not have any current blood tests for either HCV or to check my liver status.

60. During my early treatment I asked for care assistance and the Department of Health sent me a guy called GRO-D and he was awful. On one occasion when he was with me, I collapsed in the road

screaming, urinating blood. I actually soiled myself and the guy who was supposed to be looking after me said to the police who had been called, "what time is it? I've got another appointment at 3.15." The policeman said "this is your client at the moment." I fired him immediately after. He was never of any help at all. I had collapsed before, the first time being in their offices and he freaked out on that occasion. It was the following day that I collapsed in the road, and I had to call the paramedic, not him.

61. This was all the support I was offered and there was no psychiatric treatment offered ever. I requested help many times from the social worker. I asked for a carer, for counselling etc but I never received anything. I never asked Dr Grant as I didn't want him to stop the treatment so I used to put a brave face on it, an act when in front of him.

62. I was in assisted housing and when I was in the wheelchair as I've already said they put me in a tower block in GRO-D on the fifteenth floor. The elevator broke down for 3 weeks. I was critically ill at the time and couldn't get out or do any shopping, deal with bills or get medicines that I needed. I was almost a prisoner.

63. That's why I got rehoused from the tower block as the GP, Dr Grant and Dr Shah from Birmingham wrote letters to say that if they didn't move me, I was going to die. The place I am in now is 2 bed so they said that I didn't qualify, but the doctors said I needed 24-hour care so had to have a second bed and that I needed a full-time carer. I was moved to my current place. In the end, this arrangement only lasted for three weeks and then they said because of cutbacks my carer had to move on now. They offered me a cleaner but I turned it down. However, I'm glad now that the carer went now because it motivated me to look after myself and become self-sufficient again.

64. When I moved in, I just had a sleeping bag and an electric kettle. It took me nine months of saving £10 a week to buy the sofa and the TV. Again, the assistance was virtually non-existent.

Section 7. Financial Assistance

65. I have been informed that I applied to the Skipton Fund in March 2007. I have no recollection of this whatsoever. As far as I was concerned nobody has ever advised me to speak to them or told me that I may be eligible for assistance. I have also been informed that my application was rejected in November 2007 due to lack of proof that I had been treated with NHS blood or blood products and an instance of IV drug use. This was mentioned by Dr Grant who was my physician at the time.

66. I did not receive any rejection letter and never followed anything up as I just don't remember it at all. This would have been during my period of unsuccessful Interferon treatment which started in March 2007 when I was often completely out of it, one of the many unfortunate side effects. I was using prescribed oral morph for the pain which also affected my behaviour and mental state. Additionally, I was rehoused around this time, whilst on the medication and it is possible that the letters from Skipton went to my old address.

67. I cannot prove that I had a transfusion but I was certainly never a drug user. The instance Dr Grant refers to was one where I injured myself in the gym. I was into body building and boxing back then. It would have been around 1975/6. It was in Leicester, I snapped a muscle and ended up in hospital for a couple of weeks. During my treatment I received Stromba injections to help repair my muscle. Later, I was sent to private clinic and had further steroid to assist my ongoing recovery. The injections at the hospital were administered intravenously and that is the only time I have taken any sort of drug in that manner. I did discuss this with Dr Grant and I believe he has misconstrued the incident.

68. I have never heard of the English Infected Blood Support Scheme.

69. I live off my pension at the moment. I have been on disability and assisted rent since just after my first treatment. It was pride that held me off going on it during the first treatment. I thought I'd recover and go back to work.

Section 8. Other Issues

70. I also met the "Non-Responders" (group for people who don't respond to treatment) through the Trust who taught me how to look after myself and change my diet. I think the only reason I survived was through information given to me by other sufferers, because the diet really changed everything for me. I do yoga, I do swimming, stretching, walking, cycling. I don't eat meat or cheese and only drink goats' milk. I moved into my current accommodation in 2016, whilst I was still in the wheelchair, but whilst here I have stopped using the wheelchair altogether and in fact had cut back on its use after having the Harvoni treatment in 2015.

71. Sam May, Head of Support Services for The Hep C Trust is an incredible woman and has always been very supportive. She said to me that the good news is that you know you have HCV so you can do something about it. A lot of people don't know they have it, and so they don't have the chance to do something before it's too late.

72. I'm also really grateful to the Hepatitis C Trust for all the work they do to raise awareness about HCV and improve care and support for sufferers.

73. The way I felt when it first happened, I used to call up the Trust to say "what is required, mobile units to tour the country?" to make people more aware of this virus. People should go to universities and talk to students to try and raise awareness.

74. I am happy with the NHS because without them, I wouldn't be here so I owe my life to great doctors, great surgeons and great medicine and

science. I have been to the Royal Society of Medicine on numerous occasions and one of the doctors said he could do his whole thesis just on me. Without medicine and doctors, where would we be.

75. I'm really grateful to the drug companies for inventing Harvoni as without it I would have been dead.

76. Why has it taken the government so long to do this (launch a public inquiry) and why did so many people have to die? You look at other countries like America and Germany and France, and wonder why has it taken so long here? People died who didn't need to. People don't even know that there is treatment these days. I am really grateful for any member of parliament, social worker, doctor etc who campaigned to get the cost down from £300,000. It is about £10,000 now for the course.

Statement of Truth

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

Signed

GRO-C

Dated 22ND DECEMBER 2021