

ANONYMOUS

Witness Name:

Statement No.: WITN1899001

Exhibits: 0

Dated: 16 February 2019

WITNESS STATEMENT OF
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is My date of birth and address are known to the Inquiry.
2. I live alone in West London. My mother lives just outside of London and the rest of my family live all over the world.

Section 2: How Infected

3. On the morning of either the 18 or 19 September I was playing in a friend's garden whereupon I climbed up on a wall to gain better purchase in order to swing our little brothers who were on a gondola swing. As they cried

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4. On [GRO-B] I was admitted to [GRO-B] [GRO-B] Chelsea and Westminster, with stage IV osteomyelitis and stage IV septicaemia. I had been sick at boarding school for a couple of months beforehand but my condition had gone

GRO-B

[GRO-B] One of the symptoms of osteomyelitis is that it makes you hypothermic. Back then, part of the general treatment for stage IV osteomyelitis and stage IV septicaemia was to administer blood products, I think it served to boost the immune system, either that or to stimulate the circulation of blood around the area. On 28 December [GRO-B] I was taken to

GRO-B

administered the blood products alongside intravenous antibiotics sometime during the period [GRO-B] I was in the hospital for around three weeks.

5. I know that I was given a transfusion in [GRO-B] because my mum has written and continues to write everything down in diaries; she was writing in her diary at the time because my father was dying of terminal cancer

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and she needed to record everything that was happening with the experimental treatment for him, so, my mum did this with me too. She has kept these diaries.

6. It is my belief that I became infected as a result of the administration of blood

GRO-B

phase of the infection. I understand that the gastroenterologist I went to see believes that my infection is as a result of the blood transfusion. In any event, the intensity of the sickness following the operation in GRO-B was astonishing and I have never experienced anything quite like it since. I was vomiting, had headache and high fever; the sickness was relentless and went on and on for days. Upon investigation, the visiting doctor determined that amongst other things, I also had a swollen liver. The first diagnosis was that it was a bilious attack. When the doctor returned four days later, he took blood and said that he was looking for hepatitis A and/or hepatitis B. I returned to school ten days later and I recall that I was informed by my mum; maybe by letter, that there was nothing to worry about, that everything had come back negative but the doctor had said that there might be other things floating around. I am not sure what this meant. The symptoms eventually dissipated but I recall odd occurrences of other symptoms from time-to-time. For example, approximately two years later I suddenly developed a chronic itch from head to foot, underneath the skin.

7. No information was provided to me or my family about the risk of being exposed to infection prior to the receipt of the blood transfusion or the blood products.
8. I was infected by the provision of either the blood or the blood products with hepatitis C (HCV).

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9. Back in [GRO-B] I remember not feeling very well. Actually, I had not been feeling very well since around [GRO-B]; the feeling of being unwell was intermittent over the course of those years. I remember being very, very tired; I would itch and get headaches and a pain in the tip of my right shoulder. I also got tummy upsets a lot. But, no one symptom was very serious; I just had a general feeling of being unwell. I observed that I did not have the energy of friends the same age. I could not put my finger on why. For a long time, I deemed my malaise as not bad enough to necessitate a visit to the doctor. I assumed it was a lifestyle thing because I was working very hard and so I tried to address that. I tried to work less hard and do more sports and I was messing around with my diet. I even stopped drinking alcohol and I have not drunk it since. After around one year of this, I started to get really bad headaches. One day, I bumped into a friend of mine who was working as a psychologist in rehabilitation with drug users. He had been really worried about his own health and told me about symptoms and about the fact that he had just been diagnosed with hepatitis C. He apparently got it while living in Berlin many years beforehand. When he was telling me about the symptoms something about them really resonated with me. I was very concerned. At the time, we did not know whether or not the virus could be sexually transmitted. I went to the doctor who did not want to test me for it; he was of the opinion that I could not have contracted it. I insisted. He eventually relented and said he would do a HIV test as well. A couple of weeks later, [GRO-B] I was called by my GP to come to see him. He told me there was good and bad news. He told me I had not contracted HIV but that I contracted hepatitis C. He asked me if I had been an intravenous drug user, I said no, and he asked me how many sexual partners I had. I told him it was none of his business but that I had few enough that I could get hold of them all in an afternoon. At that time, I had been in a very long term relationship with one woman and prior to that there were a few girls whom I knew. I got hold of them all and none of them had it.
10. My doctor; [GRO-B] told me I had the infection. He said that not a lot was known about it and that he needed to refer me to gastroenterology at [GRO-B]

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GRO-B When I visited the hospital, during the first or second appointment I went through my medical history in detail with the hepatitis C nurse. One of the questions they asked was whether I had bouts of itching as a child, I said that I had. I relayed that I had perhaps four or five other bouts. It was their view that I had got the GRO-B

GRO-B

GRO-B The gastroenterology consultant gave me information about the infection but only after I had already been to see him a few times. He told me that I should treat it seriously, understand that it is a long term chronic illness and that my life was not in danger today, but, if I was not treated pretty soon the percentages would swing the other way.

11. I do not remember whether I was given adequate information to help me understand and manage the infection. I became great friends with my consultant and over time, and I eventually learned a great deal about it.
12. I was diagnosed fairly early in GRO-B. The medical field did not know what they were dealing with at the time. I went out and found out as much as I possibly could all of the time. It was easy for me because I knew and know a lot of doctors. Also, I know doctors in America where information was much more forthcoming.
13. It was so early, no-one really knew. I cannot say they did a bad job because I am pretty sure I am the first person that my doctor told had contracted hepatitis C.
14. I was told to not let my girlfriend use my razor blades, my toothbrush, and to use condoms.

Section 3: Other infections

15. I think I received hepatitis C only.

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Section 4: Consent

16. I do not believe I was treated or tested without my knowledge, without my consent, without being given adequate or full information or for the purposes of research.

Section 5: Impact

17. The impact of the infection on my life has been significant.
18. The physical and mental effects:
19. A few short years after the initial infection strange bouts of low health began to occur. A year after the death of my father I experienced the worst case of itching I had ever experienced in my short life. Over the years I experienced rare but recurring bouts of itching, from head to foot, and it drove me crazy. By my mid-thirties the incidences of what I now know to be Hepatic Formication, became quite frequent and maddening. I cannot express how horrendous this is; in fact, during one of these itching bouts I joked that if someone gave me a gun I would blow my brains out.
20. As a teenager I caught glandular fever. The hepatitis C actually made it more like glandular fever on steroids. I lost a further eighteen months of schooling because of it and this disrupted my O levels greatly.
21. By the age of sixteen and because of illness, I had lost almost four years of education and had to spend most holidays attending a "crammer" to catch up, when I was well enough to do so.
22. I was a talented swimmer and rower. For the former I represented my county and the latter, I got within a whisper of the junior Olympic team but owing to periods of poor health I missed the proverbial boat.

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23. Slowly through the coming decades these ever-nascent and rather amorphous collection of symptoms congealed. By my mid-thirties, my physical state was getting into something more akin to that which is associated with a major illness. By this time, apertures of wellness in a vast sea of debilitating poor health began to close. What began as extemporaneous, flu-like symptoms, blossomed into, night sweats, diarrhoea and vomiting, very bad depression, rashes, muscles pain, liver pain, a feeling of complete and total exhaustion – so bad that to leave the sofa to get a glass of water was a mission in itself. When very symptomatic, every tiny chore became a huge challenge. But, worst of all was the itching and the poor mental acuity, since I rely on high performance intellectual probity coupled with creative energy for my livelihood. This was taken from me; slowly at first, but nevertheless taken.
24. In the late 1990s my diagnosis was extended to Chronic Active Autoimmune HCV as around this time I developed problems with my immune system, particularly with my eyes and ear ducts. Of the latter I have lost 60 percent due to Sjorgens syndrome. By thirty, arthritis began to be extant and I have it in virtually every major joint and my neck vertebrae too.
25. The mental anguish from dealing with this disease is twofold. First, HCV made me very depressed and secondly, the attending social and economic problems that accompany chronic disease added to the depression and desperation.
26. I have experienced further medical complications and conditions that have resulted from the infection.
27. Along with the Sjorgen's syndrome, arthritis and general inflammatory disease; the latter a type of malady not present in any other member of my family, there are two other life impacting problems that like the above have not abated since clearing the virus a little over two years ago.
28. The first of these are the myalgic encephalomyelitis (M.E.) like symptoms.

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These are so bad that most days I cannot stay awake for more than ten hours and will fall asleep just about anywhere. Every scintilla of my being is screaming, "lie-down"; therefore, the urgency to do so is continual and oppressive and greatly impacts my life. I cannot overstate how much this serves to hold me back from doing anything meaningful in my life, all the while desiring to do quite the opposite.

29. Quite recently it was discovered while visiting family in America that HCV has undermined my endocrine system quite badly. I find in America that doctors are better versed on the impact HCV on oneself and also more inclined to give important and valuable information about it, should one wish to receive it. Back in London I am having a hell of a time getting the NHS galvanised to replicate the test done privately in Los Angeles, but to no avail. I feel as though I am being failed time and time again. One would think that a GP on learning his patient is hardly producing any vital hormones, in particular HGH and DHEA, would be concerned. Quite the opposite, since endocrinology is greatly overlooked I am not surprised when my GP tells me he has no idea what either of these hormones are; this is highly illustrative of the type of well-meaning obduracy one often experiences when dealing with the complex and time-consuming aftermath of HCV.
30. I participated in a drug trial of interferon and ribavirin in around [GRO-B] I stopped in the fifth week because I caught pneumonia. I then had treatment of peg-interferon and ribavirin in [GRO-B]. This did not clear the virus. My third lot of treatment took place in [GRO-B] at the NHS Chelsea and Westminster Hospital in London. There I received a second generation drug with ribavirin in [GRO-B] I am pleased to say that it cleared the viral count.
31. The obstacles to obtaining treatment were tremendous. On the first occasion it took 18 months of my specialist pulling strings to get me onto a drug trial as my local council refused to pay for the very expensive treatment. This was a double-blind drug trial and fortunately I got both drugs. My last treatment was in [GRO-B] and as my HCV had progressed to "end-stage" in [GRO-B] I was bumped

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up to a spot near the top of the treatment queue. But, I got caught out by the spat between the NHS and NICE that spanned a few years, during which time only a handful of people (literally four) just ahead of me were treated. The three and a half year hold up was just awful. When a person goes end-stage, what is left of their health can dissipate very quickly, as it did with my dear friend and [GRO-B]. She died within six months of being diagnosed as end-stage. Luckily, I held on. Those years were no more strenuous than the previous fifteen. No, the previous fifteen years my life consisted of managing a conveyor belt of high impact life problems, all of which were about or directly connected to, dealing with chronic HCV infection.

32. Yes, in [GRO-B] I was meant to be given third generation drugs such as harvoni but the hospital couldn't afford it so they supplemented my treatment with ribavirin; an old drug with a very unpleasant side effect profile, thus putting me through a third very nasty treatment. I was told of the drug supplementation the day the treatment started.
33. The interferon and ribavirin treatment for me was like visiting Hell. The moment these drugs hit my system a fever commenced that never let up the entire time. Then, my hair started to fall out. The drugs shifted my consciousness so malevolently I thought I was going mad; this never let up. I was in a continual state of altered awareness, depressed, agitated, going sleepless while it felt an anvil was smashing joints. My mouth became filled with ulcers, I developed eczema, still have it today and I suddenly became allergic to just about everything, including house dust. I had never suffered from allergies prior to the treatment with interferon. But, while being treated I became asthmatic and remained so for a good ten years afterwards. These days I do get asthma attacks but infrequently and not nearly as intense. During the decade after treatment I would have bad reactions to just about anything. The worst of these was to common household dust. On contact with it my entire face would swell up like a tomato, an itchy rash would appear and I would feel a weird sickly lightheaded sensation. Although my immune response has dampened down I

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still have real problems with house dust. During the treatment I felt seasick the entire time. The world was literally swaying side-to-side, accompanied by nausea, terrible headaches, a metal taste in the mouth and an absence of appetite. The last treatment was not as intense and did not make my interferon induced allergies get worse, but it was difficult when it wasn't meant to be; as the hospital reneged on a treatment regime with fewer side effects in favour of a cheaper one. This was despite ticking all the boxes that ought to have led to a better tolerated treatment.

34. I had two dentists refuse to treat me in the 1990s. One in London and one in Vancouver. My GP assumed the transmission of the virus must have been by some amoral vector and thus treated me poorly. On two occasions I suffered a kidney infection. I was on tour and becoming dehydrated from performing under very hot lights. When I presented him with the accident and emergency doctor's diagnosis; of a kidney infection, my GP refused to administer the antibiotics until I had undergone a complete STD blood test at the hospital. This took roughly a fortnight to achieve and another fortnight to receive back the results. Only when I came back negative for everything but HCV would he prescribe the cure. If this was not enough, the same infection reoccurred later on the same tour. My GP tried to make me go through the same rigmarole again. This is when I put my foot down and complained to the NHS. Bear in mind that on both occasions I was really suffering from this infection. My GP was told to apologise in writing to me and explain himself which he did and it was a most bizarre meeting. In fact I was embarrassed by his justifications and felt terribly uncomfortable. This is when I found out about the inconsistencies in my NHS file. In my NHS file there had been written many falsehoods, including that I was: married; had two kids; false teeth and was an intravenous drug user! None of this is remotely true, in fact I gave up drinking a year prior to discovering my HCV status, as a means to assuage liver pains and as I indicated previously, I have stayed teetotal ever since. On discovering this I went about having these inaccuracies expunged from my record; which they were, by unanimous consent. Now at least I understood why my GP was so

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prejudiced in his treatment of me. The glib way to sum up chronic HCV infection is thus, first you get it, then you go broke and finally you lose all your friends and family. And that in a nutshell is what happened to me.

35. The cost socially and privately has been huge; beyond measure. I have employed a type of benign denial about my illness, especially as I grew sicker. By not reflecting on the awfulness of it I was granted the ability to move forward, even if one step in the right direction was met with two back.
36. Until 2012, I had been in a series of long relationships that tended to culminate in the same manner. After becoming engaged and as we neared our marriage, the issue of my HCV infection would take centre stage. Usually some alarmist internet stuff like a post reporting new research that HCV is sexually transmittable would begin a long period of heart searching over passing the virus on to our offspring. In all cases this was a case of fear driven emotional thinking on the behalf of my fiancées and, who can blame them. Marriage is a big step and like me, they assume they will marry just the once; thus heaping more pressure on an already incendiary situation. After watching my father die slowly over five years, a man I greatly loved and respected, and hoping my future offspring would hold me in similar esteem, I couldn't in all moral certainty condone convincing a woman with such deep and similar concerns as my own to continue with marriage. Eventually we parted company; rinse and repeat. One thing about being chronically ill is that as the symptoms multiply and deepen and do so over a protracted time period, one makes many subconscious adjustments to accommodate them. Thus subjective in the extreme it takes an objective point of view to observe this phenomenon. **GRO-B** my two fiancées since **GRO-B** both asked me to consider this in their own ways. Hearing, "**GRO-B**" **GRO-B** isn't a question one hears everyday. On these occasions I was made to see myself from another's point of view; someone close enough to observe these small incremental compromises I made to the slow progress of HCV. Furthermore, I was privately very upset that my malady was causing a loved

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one, or anyone for that matter, duress. Thus reluctantly I stepped away from the prospect of marriage three times in all. One of these I respectfully must keep private.

37. As for my family? They are very old school. My brother and I were brought up by nannies. To reach my mother was quite a feat most of the time as there was a further obstacle in reaching her in the guise of our housekeeper. Not that we minded. My family are quite good at riding in at the last moment and helping out but it is tacitly understood that this is only for those life and death moments. We were brought up to be independent. To lean on others was vehemently dismissed as weakness. Thus, it is second nature for me to retreat and lock the world out when being set low by long bouts of ill health at the hands of HCV. I believe my family approve the way in which I have acquitted myself, since I never made a fuss or asked for special favour. Now, it may well be different for other people but this is how it was and is for me. I guess you don't miss what you've never had.

38. The problem since 2012 is that I have been unable to stay in contact with many friends at all. Even now, when technically cured, I still cannot muster the energy to do much each day. I am quite isolated. I think because my internal life is very well built out, the risk is I do not notice it as much as some people might. While it may be true I do miss not having much of a social life. HCV dictated an either or policy for such a long time, that until I couldn't any longer, I chose work over everything else. I do miss the companionship of being married and I miss not having children terribly.

GRO-B

GRO-B

Over the years I have experienced a fair old bit of discrimination in regards of my HCV status with prospective girlfriends on learning I had the virus cutting me dead rather rudely but nothing worse than that. In essence, with HCV first you lose your health, then you go broke and then you lose your friends.

39. There's no stigma attached with my HCV infection with my family since they

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know how I got it. Other people on the other hand, are very different. Once in a while someone is absolutely beastly and uses my illness against me, usually in business but once in a while in the NHS. On the whole everyone has been very sympathetic. Maybe because I don't harp on about it.

40. There have been educational, work related and financial effects.

41. Educational effects: I lost almost four years of schooling between ages eight and sixteen and had to attend a "crammer" in the holidays to catch up. In my teen years the specialists tried to locate the mystery "x" factor that was exacerbating what was a rather severe case of Glandular Fever caught from my first girlfriend, GRO-B at age thirteen and a half. I was sent round a litany of specialists in a bid to discover what was supercharging what should be a rather common infection. Of course this mystery second malady was perhaps beyond the scope of medicine during the mid-1970s. As an avid swimmer and rower at county and country level respectively, big hopes were placed on my athletic prowess. By the age of fifteen my times became erratic. For days at a time I would feel severely under the weather. My resulting times would often mirror this, leaving the training staff annoyed at me. Just for the record, I am no precious snowflake. Boarding schools back then were very tough and put a huge emphasis on discipline. It was in that environment that I excelled despite the hardships of bad and meagre food, being over trained and competed. Sport was the way that I gained acceptance, so I had a lot of myself invested on continuing success in the swimming pool and on the river. Pretty soon I gained a reputation for being unreliable and this was down to posting those inconsistent times. This criticism became a bugbear of mine because I loathe letting my team down. Indeed, later in life as I tried to negotiate my career around burgeoning HCV symptoms, I was sensible to the fear of letting people down. Thus I rarely ever did; however, that was and is at the expense to myself. It should be noted that at the age of twelve, I had this intense bout of itching. My mother and grandmother put it down to a psychosomatic presentation, in reply to my father's recent death. These itching attacks

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occurred seldom but when they did, I felt like ending it all, such was the intensity of them. The attacks continued every few years until my thirties when they increased quite dramatically from there on in. It was at that time I learnt that this was Hepatic Formication.

42. I went up to GRO-B in the GRO-B and reluctantly stepped away after long discussions with my master and members of my college. They kindly allowed me five years to sit my finals and I was allowed within limits to study my final year at home. I was so disheartened by not being able to finish my degree. I loved GRO-B and became an exemplar of the axiom that education is wasted on the young. When I understood I was allowed to attend any lecture I wished and this privilege extended to GRO-B also, I was like a kid in a sweet shop despite being in my mid-thirties. This alone served as reason to fight against the enveloping malaise of HCV. Attending lectures by the greatest living minds, novel minds, in physics, mathematics, neuroscience, watching new fields such as epi-biology emerge and getting to interact with such in its infancy was exhilarating; it made me consider my decision to decline the offer to head the new department of "GRO-B" back in GRO-B a few months prior to my diagnosis. The second year of my degree course coincided with a severe uptake in HCV activity. Reluctantly, I stepped away, hoping my health would improve. It did not. My college very kindly offered to keep my degree open for a period of five years, in order I might complete it later. My health did not improve. On the contrary it worsened. These bouts of illness became more frequent and consistently longer in duration. As I mentioned by the end of the millennia I went back to study partly because I was worried about my ability to endure a long album project or tour. This three year hiatus was about taking time out to figure out how and if I should continue my vocation since it was growing patently clear to me that I could no longer compete (without risking the careers of others) due to the progression of my illness. It was during this time that HCV transformed from being a nuisance one might work around, to an edifice of obdurate intransigence, blocking out the future entirely, such was its mass.

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43. Since 2012 I have not been idle. I taught myself higher mathematics, and physics. My studies culminated in winning a place at **GRO-B**
GRO-B If by good fortune I can discover how to ameliorate my severe fatigue and brain fog, I may consider attending this August academic institution.

44. Work-related effects: Over the course of a four decade long career the long shadow of HCV hung over a vast portion and was very difficult, and most recently impossible to negotiate. The devastating symptoms associated with HCV infection, kicked my career into the long grass four times. Of the initial three, I was able to improvise a solution, whether a slight refocus or a massive shift in emphasis, much was required of me to re-establish myself after the long absences I had to take from my professional field. **GRO-B**

GRO-B

Thanks largely to the **GRO-B**

and opt instead to move abroad and take an apprenticeship in sound engineering; I was armed with many more skills than my peers, meaning that when HCV got really troublesome in my thirties I was granted some latitude when navigating a path around the symptoms concomitant with long term infection. Please see Section 8 for more information regarding my career. Everyone experiences career setbacks. However, compounding the pressure of working at the very pinnacle of a highly competitive field was the added weight of trying to manage the HCV symptoms. Of these, brain fog (which I still suffer from time-to-time) and a ghastly debilitating lack of energy, what my specialist called, "M.E. like symptoms", hampered me most of the time in between bouts of highly symptomatic viral activity which rendered me housebound and often bed ridden for days, and beyond my twenties, for weeks and months. About the time of the new millennia bouts of ill health outweighed

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the periods of relative normality. As the new century progressed these bouts of ill health began deepening, lasting far longer and new symptoms appeared. In the melee I lost two homes. I sold my home a second time to bankroll treatment in 2001. I cannot begin to put a number to the total financial loss incurred from HCV; moreover, losing the chance to marry and have children actually means a lot more to me than money. By the early 2000s my health began precluding certain aspects of my career completely.

GRO-B

GRO-B

45.

GRO-B

46. In around GRO-B; I forget when, the specialists deemed my HCV had entered end-stage infection. I succumbed to new depths of malicious symptomatic hell.

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GRO-B

GRO-B

That was the plan. That plan did not happen.

NICE and The NHS got into a spat a year or so later and this meant my hospital didn't have the funds to treat me. The following years were dire. I lived in abject penury, ill and alone. I received a Stage 1 Skipton Find payment a year prior to my treatment and this helped immensely. Despite being a priority case because I was so ill and even though I was right at the top of my hospital's treatment list, they weren't able to fund my treatment until the end of 2016. Treatment has made a big difference. For a start my food isn't passing straight through me without being digested and I don't have to change the sheets

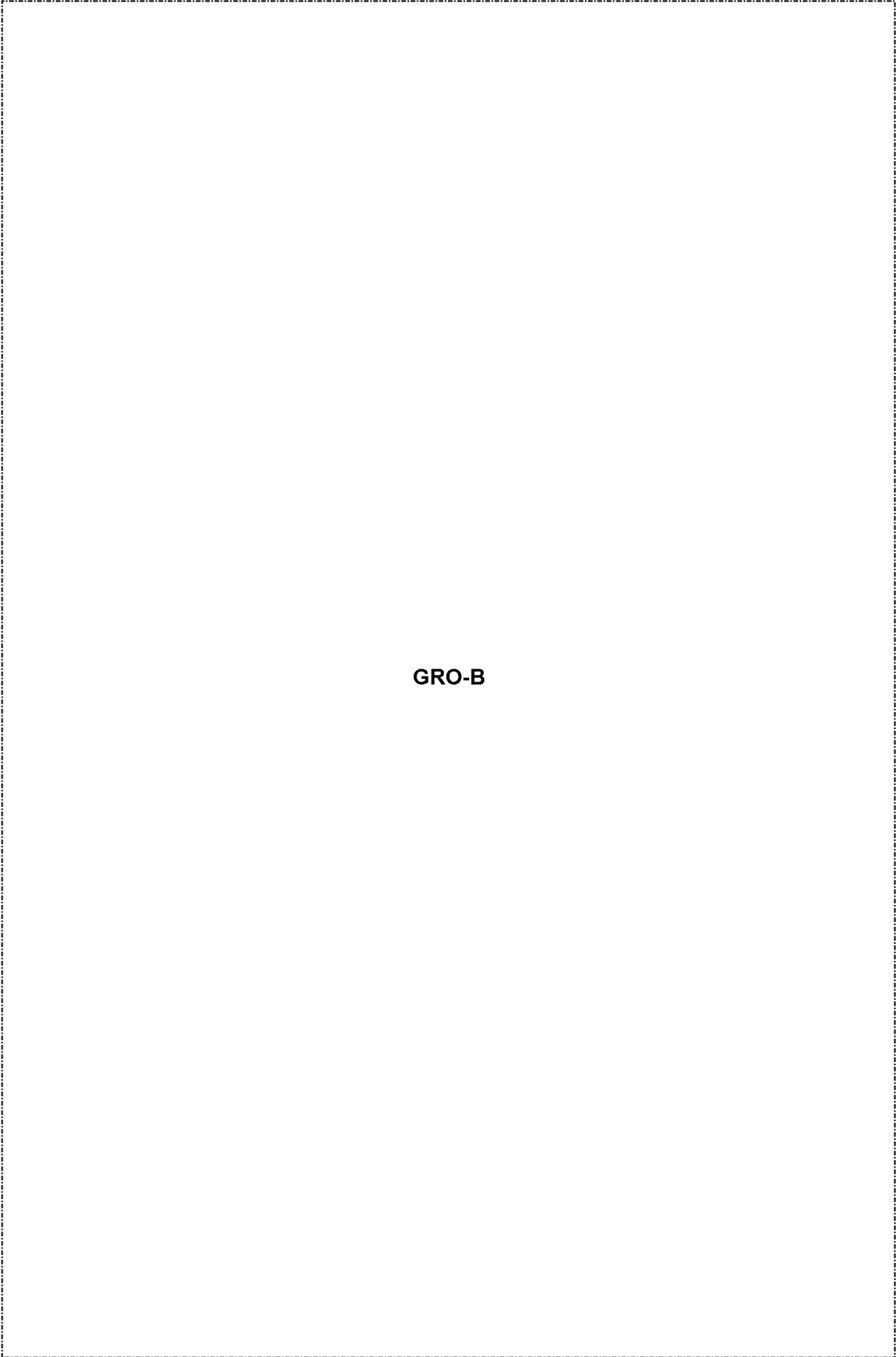
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nightly owing to the night sweats, plus many other improvements. But the M.E.-like symptoms have continued, as mentioned previously. My specialist says this is reported in about 40 percent of people with two or three decades of HCV infection. This leaves me with a huge upward climb. Six years of musical ideas flying around my mind but without the energy to effectively make anything of them. I have left no stone unturned in a quest to assuage the very limiting proportions of these M.E.-like symptoms. I was told that falling asleep all the time and having to sleep for upward of twelve hours a night was a symptom of end-stage HCV infection. Yet, I am technically cured and this symptom still remains. As you might well imagine this state of affairs is extremely frustrating for me as not only does it severely limit my vocation prospects but also my ability to reform lost friendships and social ties. Very troubling.

47. In conclusion, from the mid 1990s, my career options were narrowed by the progressive nature of HCV infection. Three times my career was brought down; I managed to rebuild it by working around my limitations. But, by 2012 I was too ill to work at all. Since then I have struggled greatly and although I am itching to get back to work I simply do not have the concomitant level of health to achieve this but, I remain optimistic.

48. Financial effects:

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49. I believe that I have answered this question at paragraph 13 above.

Section 6: Treatment/Care/Support

50. Support has been negligible and receiving treatment has been very difficult in the UK. The first time I was treated back in GRO-B my gastroenterologist, spent months shuffling paperwork to get me and several of his patients on a drug trial as this was the only method to obtain treatment; since interferon and ribavirin, was prohibitively expensive back then. My experience of the trial isn't important and the outcome has been addressed already. The drama surrounding my third treatment (the second in the UK) is a travesty of errors. I was stuck at the top of the treatment list, prioritised on need, just as the NHS refused to treat HCV patients over the spat with NICE over who was going to foot the bill. This meant three years living with end stage HCV languishing in poverty alone with no help.

51. No counselling has ever been offered but I did go to a private psychoanalyst for three years in order to comprehend HCV infection and how violated I felt. When I went back to study I stopped analysis because I couldn't afford it and return to education.

Section 7: Financial Assistance

52. I have received financial assistance from Skipton Fund and the England Infected Blood Support Scheme (EIBSS).

53. I found out about the Skipton Fund through The Hepatitis C Trust sometime in

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2009 or 2010. I stumbled upon it, no-one told me about it.

54.

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55. After receiving the initial paperwork I began collating the commensurate evidence. Then, to my dismay I discovered my medical notes prior to 1992 were missing. Quite how this happened might be because I signed a waiver for my records to be accessed in the mid-nineties during the Penrose Inquiry. Or perhaps they were lost when I moved just a year or so prior. Illness precluded me taking any more steps for a few years other than gathering information about how and why my records were missing. I know for a fact my previous GPs circa 1993 had them since

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GRO-B I searched for these missing records diligently. I even got permission to conduct a hand search at the depository in Brentford. GRO-B

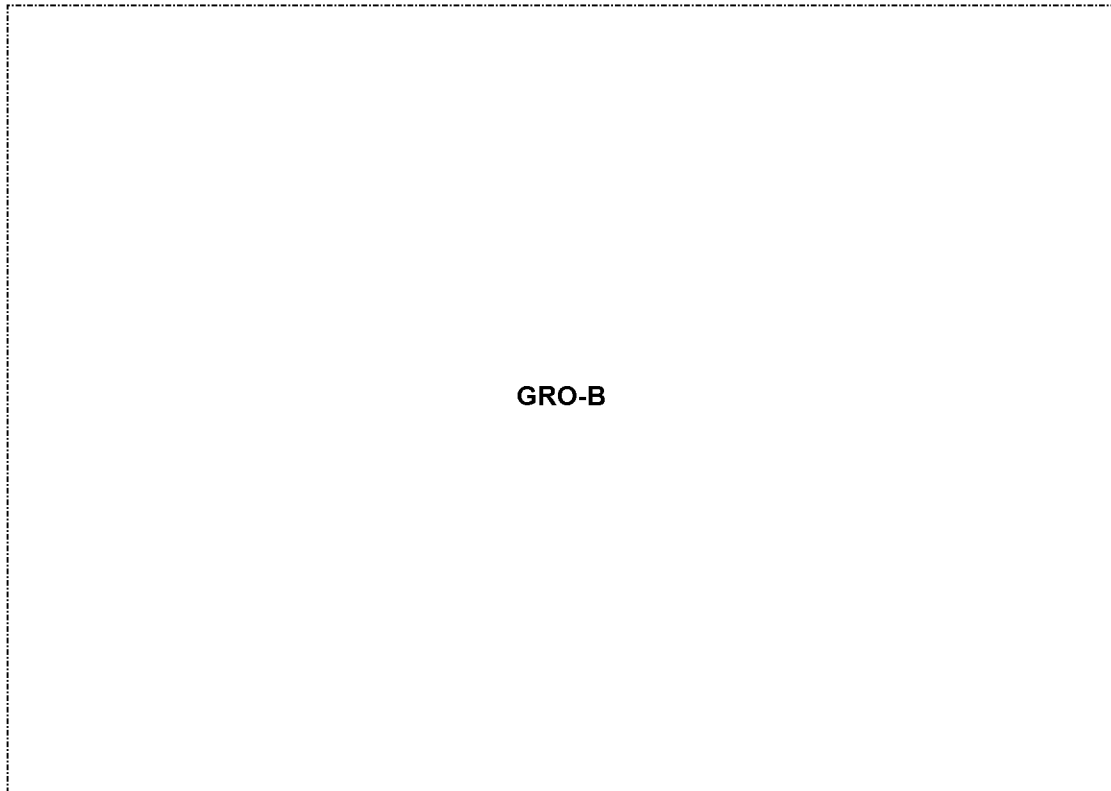
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Without my record I felt applying to The Skipton Fund a waste of time. Then in 2015, I was talking to a senior officer of The Hepatitis C Trust and was told that I ought to apply as soon as possible, to The Skipton Fund since they take into account that some people may not possess their childhood records since the NHS destroyed many of them, quite legally during the 1980s and 1990s. Happily my application for Stage One Skipton Fund was awarded in November 2015 and Stage Two the following year. This fund has been a saviour. It got me out of poverty and I was able to pay off the massive amounts of debt one accumulates when seriously ill for so long. Also it means I can live near where I grew up so I am no longer quite so alienated. Were it not for The Skipton Fund I am not sure if I would be alive right now. I mean it. HCV has left me with a slew of health problems that in other countries are openly accepted as possible side effects of long term infection. For example my endocrine system is out of whack. I no

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longer make anything near the NICE accepted levels for Dehydroepiandrosterone (DHEA) and Human Growth Hormone (HGH). My family in America, kindly paid for me to visit a specialist who wrote a long letter for my GP here. Unfortunately my GP hasn't a clue about anything that was written in this letter. But at least, albeit it painfully slowly, these problems are being addressed. Meanwhile, thanks to the EIBSS I can afford to supplement a little portion of the slack from the NHS by seeking help privately. The dilemma is that these seriously inadequate levels of important hormones may point to a deeper cause, one that will cost a fortune in relative terms if one is to pursue such an end privately. Thus I have had to change horses mid-stream. In effect I will do anything I must, within reason, to get well enough to get back to my vocation.

56.



57. I do not recall there being any preconditions imposed on the making of an application for or the grant of financial assistance.
58. I am not happy the EIBSS is run by the NHS.

Section 8: Other Issues

59. GRO-B As such I attended two or three meetings with them where we went into some depth of my experiences. I was surprised that nothing much happened from that Inquiry. There are no other issues in relation to which I consider I have evidence.
60. I do not have any other documents which might be relevant to the Inquiry's Terms of Reference.
61. Regarding the conduct of the Inquiry, my sincere hope is that provisions will be enacted so this travesty will not happen again. I spoke to others about this very question but I do not share their desire for blood, however metaphorical their desire. Those responsible for this murderous debacle are either long dead or in their dotage; one might speculate this is why the Inquiry found no political will to proceed until now.
62. In relation to what I hope will be achieved by this Inquiry, I hope to be made financially whole. I, along with most others, have lost out on more than money. I had to rebuild my career four times because it was brought down by my poor health. I've lost so much more, family, marriage, owning a home - sold it to pay for living expenses while ill with hepatitis C. Nothing can be done about the majority of this but the government sure as hell can recompense us financially. It is too late to accept the NHS's hollow apologies.
63. I have encountered experiences where medics were not being candid with me about my condition. The gastroenterology department at The Chelsea and Westminster Hospital always minimise the problems you present with and it was not until being checked out by a family GP in America that I was given the full picture.
64. GRO-B

ANONYMOUS

GRO-B

65. I have concerns about the accuracy and completeness of my medical records.

GRO-B

I gave the panel permission to access my medical records. I signed a waiver so that they could access these records and I do not know whether it is a causation or correlation but all of my medical records prior to 1990 disappeared at about that time.

GRO-B

GRO-B

I recalled having a conversation with my GP six months prior to signing the waiver and discussing the detail of early procedures that the GP was able to access and we referred to.

66. I have experienced problems trying to obtain access to my medical records for years. I spent years hunting the missing records down but to no avail. I even went as far as getting written permission to a search of the Brentford record depository, something I undertook in 2005 but this did not yield a positive result.

67. I feel that I have been treated less than favourably by certain medical professionals throughout my journey with this condition. As I explained above, my initial GP treated me with extreme prejudice; assuming I got it through nefarious means coloured his treatment and attitude toward me.

GRO-B

GRO-B

GRO-B

Statement of Truth

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

Signed: GRO-B

Full Name: GRO-B

Date: 16.02.18