

Witness Name: J W Ainsworth

Statement No: WITN1069001

Exhibits: WITN1069002-3

Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JONATHAN WILLIAM AINSWORTH

I, Jonathan William Ainsworth will say as follows:-

Section 1: Introduction

1. My name is Jonathan William Ainsworth. My date of birth is GRO-C 1980 and I live at GRO-C Manchester, GRO-C I live with my partner, Linda and am currently unable to work due to Chronic Fatigue Syndrome which arises from my Hepatitis C infection (genotype 1a).
2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2: How Infected

3. I was diagnosed with severe Haemophilia B when I was around 18 months old. This means that I do not have enough Factor IX in my blood. Before this, doctors knew that there was something wrong with me but they could not

work out what it was. After testing me for cancers and various other conditions, they managed to correctly diagnose me as a haemophiliac.

4. Throughout my childhood I had regular trips to the Manchester Children's Hospital in Salford to receive treatment for bruises and bleeding episodes. My regular haematologist was Dr Richard Stephens. At the age of 18 I moved to be treated at Manchester Royal Infirmary.
5. When I was 4-5 years old and had just started primary school, I was pushed against a wall by another boy and the back of my head split open. I was taken to hospital for treatment.
6. I remember my mother telling me that I had been treated with blood products from America on this occasion as there was a shortage of what I normally received.
7. Having reviewed my Haemophilia Database records I note that I received the Cutter product on GRO-C 1985 which was the day before my 5th birthday.
8. When I was around 5 years old I vividly remember being seen by doctors who were wearing big masks and thick gloves. I remember asking why they were wearing that, and they told me something along the lines of them having to take precautions as there had been some kind of mix up.
9. Not long after this incident my parents told me I had something called Non A – Non B Hepatitis. This didn't mean much to me as I was so young, and I continued to live a normal life. I believe that I was also tested for HIV at that time although I have no direct recollection of this.
10. I have now been provided with my records from the UKHCDO National Haemophilia Database and these are attached to my statement as "WITN1069002". I note that I was treated with Factor IX in 1981 (Manchester), 1982 (Manchester), 1982 (Lancaster), 1983 (Manchester), 1984 (Manchester) and 1984 (Bangor) all of which pre dated the incident that

I recall where I cut my head open. I have never been told when I was infected with Hepatitis C.

11. When I started school I was a quick learner and achieved well, especially in mathematics and grammar, although I noticed that when it came to reading I struggled with concentration despite the fact I could read the words.
12. At the age of 8 I was excelling at school and doing quite well in most subjects, however my concentration problems were becoming more apparent to me.
13. Sitting in a particular maths lesson I had a long hard think to try and understand why this was happening. Two of my friends and I were the high achievers of the subject and we were sat together in the lesson. They were sat reading away through the books and listening to the teacher whilst working. I fully understood the work and listening wasn't a problem, but I felt like I was floating and had to keep having breaks from reading and re-tuning into the lesson. This was a constant occurrence. 'Am I lazy? No. Do I like the subject? Yes. Do other people feel like this? I don't know, surely not!' 'Very strange' I thought. I shrugged it off and assumed it must be a part of growing up with my body changing etc, but this always stayed in the back of my mind.
14. When I was 10 years old we received a letter in the post explaining that I had contracted Hepatitis C through contaminated blood products. The letter was the first time that they effectively said that they had been able to isolate the virus and give it a proper name.
15. This was the first time I had heard of Hepatitis C, although I had heard my parents mention something about Non A Non B Hepatitis prior to this. I was not surprised that I had been diagnosed with something. I knew there was something wrong with me from an early age that I specifically thought about retrospectively at the age of 8. In this sense, it was almost refreshing knowing that there was a reason why I felt the way I did, even though at this stage there was no known connection with fatigue at this time.

16. Even at such a young age I was still surprised that they had sent me a letter telling me of my diagnosis rather than calling me in for a meeting and telling me in person. It felt extremely impersonal and as though they were just printing and posting a standardised letter to all the people they had infected, which is likely exactly what they were doing.

17. After my diagnosis we attended some clinic appointments but were told very little about the disease. I was not told anything about the future damage to my liver or about the risks of transmission.

Section 3: Other Infections

18. I believe that my Chronic Fatigue Syndrome is Post Viral Chronic Fatigue Syndrome which has arisen as a direct result of my HCV infection. The impact of this on my life is described further below.

19. My UKHCDO National Haemophilia Database records show that I was tested for HIV in February 1985 and April 1986.

20. In my early 20's I also received a letter warning me that I may have been exposed to vCJD, and that I would have to let doctors know before any form of surgery. I remember thinking that this was just part and parcel of everything else and that I had probably been exposed to all sorts of viruses. I note from my UKHCDO National Haemophilia Database records that I was potentially exposed to vCJD on two separate occasions.

Section 4: Consent

21. I have not had contact with my parents since I was 19, but I do not believe they were given any advice as to the risks of infected blood products.

22. I do not know if my parents consented to me being tested for Hepatitis C or HIV but they would have consented if they had been advised by my treating doctors that testing was necessary.

23. I have always felt that I have been treated like a guinea pig – particularly when it has come to being offered treatment for HCV.

Section 5: Impact

24. I currently suffer from Post Viral Chronic Fatigue Syndrome, which I have no doubt is due to the Hepatitis C infection. I have suffered from chronic fatigue for most of my life, which has left me unable to work. I constantly feel tired, fall asleep after short tasks, lack concentration, feel dizzy and unsteady and suffer from post exertional malaise. These symptoms are gradually worsening with age.

25. When I wake up in the morning after at least 10 hours sleep I always feel the exact same foginess as I did before I went to bed and am un-refreshed. This remains consistent until I naturally fall asleep again. Usually I need to sleep around every 5 hours for a short while to avoid feeling excessively dizzy and disorientated.

26. Tiredness throughout the day can also be very problematic if I need to go out anywhere, because if the fatigue becomes too intense I cannot stop and sleep anywhere. This results in me becoming disorientated and unsteady which can be dangerous especially when crossing roads, being in crowds of people and trying to follow directions. For example I fell over twice in the street Christmas 2016 on a visit to my GP and going to buy presents; this resulted in two black eyes and a head injury.

27. I need to be careful with general everyday tasks too such as cooking. Most of the time I'm too fatigued to cook a full meal so I either eat lightly or rely on my partner to help. Again my concentration fades quickly when I have to focus and I'm at risk of injury.

28. I find I cannot watch films on TV as I completely lose the plot of what is happening and it just appears to be a wash colours and noises. Reading books is near impossible as I lose track of the content after half a page and

have to keep going back on myself. I find that if I keep pushing to do these tasks I become incredibly tired and fall asleep. Throughout my life this has held me back from studying and achieving any kind of professional qualifications.

29. To this day I still struggle to concentrate in areas such as reading, conversations and focusing on most things such as study/work; this causes anxiety.
30. I also suffer from brain fog and forget things often. I forget names of people all of the time and when I go to the supermarket I need a complete list of the things I need which I need to follow carefully because I cannot remember them.
31. My education undoubtedly suffered as a result of the infection. Despite my fatigue and concentration issues I was still a bright student. I received the highest grade in the year for the Biology GCSE mock exam and my attendance was good, however in 1995 I was then put on my first course of treatment of Interferon.
32. The side effects of my first round of treatment were so severe my attendance for the final year of school was 31% and I failed all but one of my GCSE's (maths). I couldn't do any coursework for most of them due to illness. I was devastated.
33. The prospect of doing A levels and a degree like my friends was out of the question because I knew that my fatigue was too intense and I'd be back on the Interferon treatment by the time I hit university age. I felt like normal life was slipping through my fingers.
34. When I was 17 I started working part time in a sports shop. A year later I was essentially managing the store, however due to my fatigue I would have to sleep in my car during my break.

35. I finished working here in January 2000 as my ankle joint wore out through bleeding and arthritis. I needed to wait 18 months for the joint to be surgically fused so I was prescribed slow release codeine. I ended up on 60mg slow release tablets twice a day, which later caused addiction problems.

36. **GRO-D**
GRO-D I cut all contact with my family and became homeless, spending my nights either in bail hostels or living in a tent, until I was offered a small flat in South Manchester. **GRO-D** was also very regimented and when I lived at home **GRO-D** said things to me like "you're spreading germs around the house" **GRO-D**
GRO-D

37. I went to college and studied computing and accountancy of which I managed pass on both subjects. Work still wasn't an option due to fatigue, I found that I only had enough concentration to study and get by on a daily basis.

38. The uncertainty of not being able to work or study puts a burden on my life and I feel a strong element of hopelessness and uncertainty about what the future will hold. I am not in a position to study and build a career for myself and feel like I'm living in a world where I watch people pressing on with positive lives whilst I'm looking through the window wishing I could join in.

39. At 28 I applied for an accountancy course and managed to secure a part-time position as an accounts clerk which lasted about 8 months. At work I was falling behind because of concentration issues. I was ok working in silence and understood the workload but my communication was suffering through feeling delirious. I didn't complete the course either. I decided that it seemed a bit pointless to keep trying to succeed in this area of work due to my delirium.

40. By now I realised that I was suffering from Post Viral Chronic Fatigue Syndrome through online research of other Hepatitis C sufferers and talking to specialists.

41. At 30 I started working as a part-time computer engineer on Trafford Park which lasted for around 3 years. Mostly I was working on my own so the job suited me better. On the third year I crashed my car on the way to work through having a blackout whilst driving. My health was checked and seemed to be ok otherwise. I stopped driving for 9 months and was ok so re-applied for my license. I crashed the car twice again through unknown reasons so I stopped driving. I finished working for the company due to fatigue. Since then I have been unable to work.
42. I hate being unable to work and I feel like my life is in a void. I'm stuck at home in my flat everyday and am unable to do normal things which makes me feel frustrated and isolated. I find myself just listening to music and going out for walks when my legs are free from bleeds to distract myself from reality. If someone asks me what I do I just tell them that I am an engineer.
43. My inability to work or study has obviously impacted on my financial position, and I have had to rely on sickness and unemployment benefits for the majority of my adult life.
44. I have received treatment on four occasions to clear Hepatitis C. When I was 15 (in 1995) the doctors discussed with my parents the possibility of receiving treatment to attempt to clear the virus. I was told the Interferon could result in side effects similar to a 'mild flu', however the impact was shocking. After taking Interferon, my immune system pretty much collapsed through neutropenia. I became delirious and was borderline hallucinating at some stages. The lack of white blood cells also caused abscesses and my toenails to fall off, and I was clammy, cold and shaky. This continued for roughly 5 months before I was withdrawn from the treatment for safety reasons, however I continued to suffer and it took me a long time to recover. The treatment was not successful in clearing the virus.
45. When I was 21 (in 2001) and no longer homeless, I was given Pegylated Interferon in a further attempt to clear the virus. This time I was also taking Seroxat to help my depression. Although I was better prepared for the

treatment this time and knew what to expect physically and mentally, after a few months of suffering from the same side effects I was withdrawn from the treatment due to neutropenia and mental instability.

46. When I was 25 (in 2005), I tried the Hepatitis C treatment for a third time. This time a combination of Pegylated Interferon, Ribavirin, Granocyte (to stop neutropenia) and Seroxat. I again suffered from the same terrible side effects, and although I managed to complete the course of treatment it proved to be unsuccessful. After completing the 12 month course it took me at least a further 6 months to recover. I split from my girlfriend Linda for this year as I didn't want her to be around me whilst I was on this treatment as it would have been unfair for her to deal with the trauma of me taking it; I just wanted her to enjoy her life.

47. In 2014, when I was 33, I tried the Hepatitis C treatment again which consisted of: Pegylated Interferon, Ribavirin, Boceprevir, Granocyte and Seroxat. This time I was also vomiting a lot throughout the treatment as well as all of the other side effects, and by the end of the treatment as with the previous courses I had lost so much weight you couldn't even pinch my body fat. However the treatment worked and I've remained clear of the virus since. Although the treatment was successful the fatigue still remains and is worse than ever. I feel exactly the same as I did before I was cleared of the virus. If I wasn't told that I had cleared the virus I wouldn't know.

48. Throughout these treatments I felt like I was being used as a guinea pig, where they would give me drugs with no idea what would happen to me and simply observe the results. I always felt that the doctors asked me a lot of questions about my difficulties but never provided any help or advice. I was treated as a curiosity and my confidence in medical professionals has dwindled over the years as a result of this experience.

49. I was also not offered any counselling when receiving treatment.

50. Every time I had treatment it would take up to 6 months for the side effects to clear.
51. I have received derogatory comments about my infection but I generally brush these off. I only really tell people on a need to know basis and as such my suffering from the stigma of Hepatitis C has been limited.
52. My conditions and the treatments I have received have had a big impact on my relationship with Linda. At times I haven't been easy to live with, especially when I was receiving treatment. I tend to just set myself one task a day due to my fatigue and concentration issues, and Linda therefore has to help me a lot.
53. Although I am now clear of the virus I have not felt any improvement in my fatigue which is the major impact and problem in my day to day life. The only benefit of clearing the virus for me has been that there is now less chance of my dying from Hepatitis C.
54. I have had a few liver scans but they cannot do a liver biopsy because of my severe haemophilia and therefore I don't really know what state my liver is in.
55. I am also unable to obtain life insurance due to my condition which means I would never be able to get a mortgage if I wanted one.
56. I feel that my infection has denied me a normal life and any sense of identity. I cannot work because of my fatigue. I have no money to take part in any activities because I am reliant on benefits. I feel incredibly isolated and trapped in my life with no prospect of any improvement. It is as though I am always looking out at the world but not really part of it.
57. During the course of my recent therapy the Trainee in Adult Psychiatry with whom I had my initial appointment, Dr Nagle, wrote a detailed letter to my GP which set out the things we discussed in my initial assessment. A copy of this letter is attached to my statement as "**WITN1069003**". It sets out my difficult early life history as well as my feelings about the impact that Hepatitis C and the treatment for the same had had on my life and I would ask the Inquiry to read it in conjunction with my statement.

Section 6: Treatment/Care/Support

58. I have never really had much difficulty in obtaining treatment for Hepatitis C. If anything it sometimes felt like they were encouraging me to receive treatment so they could test their new drugs on me. I still often receive invitations to clinical trials for my haemophilia. The side effects of my various treatments are discussed in detail above.
59. Counselling was never made available as a result of my infection, other than over the phone counselling from the Skipton Fund which I declined. Psychological support would have been extremely beneficial to me, especially when I was younger and having to endure my first course of Interferon treatment.
60. I have recently just completed some sessions of cognitive analytical therapy to help me address personal and mental issues that have arisen as a consequence of my infection. This was something I had to arrange on my own through my GP.

Section 7: Financial Assistance

61. I received the Stage 1 payment from the Skipton Fund in 2004.
62. I also receive Skipton Stage 2 SCM payments, which total around £1500 a month. These have been paid monthly since April. There is a further discretionary top-up I receive of £362 each month to 'help keep people out of poverty'.
63. I have found the Skipton Fund and the Caxton Foundation very difficult to work with. When I have spoken with them on the phone they are usually quite ignorant and very awkward.
64. I was offered counselling by them but I then discovered the counselling sessions would be done over the phone. This seemed pointless to me as I

would have no idea who was on the other end of the phone; I could have been speaking to anyone.

65. I have only ever pushed them for one thing, which was a contribution towards a respite break with my partner after my latest course of treatment. I didn't think this was too much to ask for as I had never requested any additional payments from them before, and after having to endure treatment for Hepatitis C on 4 occasions I figured this was the exact type of thing that the Caxton Foundation was set up for.

66. However, they were extremely rude and stand-offish when I asked and they were very reluctant to give me anything. Eventually, after jumping through many hoops and having my doctors write to them, they gave me a small contribution to our trip to Lanzarote.

Anonymity, disclosure and redaction

67. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

68. I confirm I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed.. GRO-C

Dated.. 11/11/2018

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

- 29.03.1981 Haemophilia B – haemophilic type b Christmas disease
- 09.05.2007 Hepatitis C failed Interferon and Ribaviron treatment
- 17.06.2009 Chronic fatigue syndrome secondary to Hep C
- 01.03.2010 GP records. MED3 issued to patient. Job seekers allowance. Hepatitis C years. Was on interferon x 3. First course during GCSEs so failed them so couldn't do A levels. Studying at college as accountant. Was on incapacity benefit. Tiredness.
- 28.01.2013 GP records. Had a collapse. 7.12.12 – blackout whilst driving and involved in low impact RTA...
- 11.03.2013 GP records. Stress related problem. Reports he has been off work since 01.03.13. Initially felt run down and stressed at work. The developed a cough and cold....
- 15.03.2013 GP records. Chronic fatigue syndrome review. Works at Trafford Park as a computer engineer – works 3/7 a week. Has CFS, hepatitis C and haemophilia B. Struggling with fatigue and working. Has been off the last two weeks – has felt better in himself with more rest. Has tried 3 rounds of treatment for hep C without success. Due to try again.
- GRO-C
- GRO-C
- 21.06.2013 GP records. Chronic fatigue syndrome review. New statement issued. Not fit for work.

01.12.2015 GP records. Absence seizure. Finished antivirals for hepatitis C. Was fainting up to x4/week for 18/12 eg collapsed in street no warning. Stopped antidepressants in March.... Neurological referral.

31.03.2016 Letter from MRI to GP. His hepatitis C was eradicated earlier last year after triple therapy. I have repeated his liver function test and hepatitis C PCR today. We will be in contact if there is a problem with these. Otherwise we will see him again in 12 month's time.

22.06.2016 Temporal lobe epilepsy.

30.03.2017 GP records. Referral to psychologist. Multiple health issues. Haemophilia. Ph hpe c. Epilepsy (presumably post bleed from haemophilia confirmed on MRI scan). Chronic fatigue. Sliding mentally. Frustrated. Stressed. Poor concentration. "Nervous breakdown" last Friday. Drinking alcohol.Not worked for ages because can't concentrate. Had variety of job. Retails. Accountant, Sound engineer. Understood work but poor concentration. Can't drive because of epilepsy. Can't read, can't concentrate. Feels like can't do much....Feels maxed out Requesting referral for psychology.

20.10.2017 Letter from Psychologist to GP. He lives with his long term girlfriend in central Manchester. He is unable to work due to multiple physical health problems and is in receipt of benefits....He has no past psychiatric history....He recounted his complex medical history:

Haemophilia B: Jonathan was diagnosed with Haemophilia B when he was 18 months old and he has been on prophylactic Factor IX injections since adolescence. Jonathan attended hospital thrice weekly on average as a child for treatment of bleeds.....His haematologist is Professor Charles Hay at MRI.

Hepatitis C – Sustained Virologicla Response: Jonathan developed Hepatitis C through contaminated blood products that were

administered prior to 1986. He underwent 4 trials of interferon therapy in 1995, 2001, 2005 and 2014 before achieving remission. Jonathan experienced psychological side effects from the early trials that were not treated with psychotropic medication. He was later treated with Paroxetine which he stayed on for several years. Jonathan recalled that he received no support from professionals when he went "off the rails" on interferon during his first trial and that he wasn't even informed of the potential psychological side effects until years later.

Temporal Lobe Epilepsy.....

Chronic Fatigue Syndrome: He believes that his CFS diagnosed stemmed from his Hepatitis C.

Jonathan spoke about feeling isolated in his illness experience....He has had to live his life cautiously and restrictively. He is currently unable to work or travel. His illnesses and their treatments can be capricious causing sudden setbacks and necessitating frequent changes in his medication regime....His confidence and trust in the medical profession has dwindled over the years. He said he was treated like a "guinea pig" during the trials of interferon and knowingly administered contaminated blood during the 1980s.....When he was speaking about his relationship with the medical profession, I sensed that he often felt he was treated like a curiosity. He said doctors asked him loads of questions about his difficulties but rarely returned any help or advice. He ended up feeling as if he was giving to them while they were taking from him which replicated the lack of support in his other relationships. Jonathan said that this made him angry but that he would never voice or show his anger.

20.06.2018 Letter from Psychologist to GP. We have been considering the interplay of Jonathan's physical health, interpersonal relationships, and adverse events in his life to consider relational patterns that may be contributing to his current difficulties.....

12.09.2018 Letter from Psychologist to GP. I have recently completed a post therapy review session following 16 sessions of cognitive analytical therapy.....His score of the CORE-OM which measures general psychological distress, reduced from 60 to 37 and has reduced slightly again to 35 at follow up.

24.09.2018 Seen in psychology clinic