

Witness Name: P S Fenton
Statement No: WITN1646001
Exhibits: WITN1646002
Dated: April 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAUL STUART FENTON

I, Paul Stuart Fenton, will say as follows:-

Section 1. Introduction

1. My name is Paul Stuart Fenton and I was born on GRO-C 1968. I live at GRO-C Cheshire GRO-C
2. I was infected with Hepatitis C via contaminated Factor IX concentrates.
3. My medical records indicate that I was also infected with Hepatitis B, in the same manner, but I was unaware of this until I saw my medical records. I attach evidence of this at **Exhibit WITN1646002**.
4. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How Infected

5. I have severe Haemophilia B, with a clotting factor of less than 0.1%, which was diagnosed when I was aged 1. There was a delay in my diagnosis

because doctors were initially looking at a deficiency of Factor VIII and not Factor IX.

6. I was initially seen at Barnsley Hospital, South Yorkshire, in 1968 before my care was transferred to the Sheffield Children's Hospital where I was treated from 1968 to 1974. My care was then moved to the Pendlebury Children's Hospital, Salford from 1974 to 1976. In 1976 my care was transferred to the Manchester Royal Infirmary (MRI) where I am still treated today.
7. I was initially treated with Cryoprecipitate before moving to Factor IX concentrates when these became available.
8. Neither my parents nor I were given any warning or advice regarding the risk of infection from Factor IX concentrates.
9. I was infected with Hepatitis C and Hepatitis B.
10. My medical records do not assist in identifying either the date of infection or the hospital at which I was infected.
11. I believe that I was told that I had Hepatitis C in the late 1990s. I attended a routine appointment at the MRI with Professor Hay. I can't remember if I was on my own, with my mother or with my partner. I remember being told in a rather "*wishy washy way*". I recall being in shock. I was just about to get married and was preparing to start a family with my partner. I think Professor Hay did mention a few vague things regarding transmission of the infection; I remember something about not sharing toothbrushes. I did not feel that I was provided with sufficient information to allow me to understand or manage the infection. I was also not furnished with adequate information regarding the risks of transmission. I also vaguely remember a nurse saying in passing "*you do know that you've got Hep C, don't you?*" However, I am not sure if this was before or after Professor Hay told me.

Section 3. Other Infections

12. I remember Professor Hay mentioning something about vCJD to me but I don't recall much about this and I don't think I received any correspondence regarding the same.

Section 4. Consent

13. I was not aware that I had Hepatitis B before I saw my medical records. I was therefore tested for this virus without my knowledge and therefore without my consent.

14. I was not told that I was going to be tested for Hepatitis C. Given that I was diagnosed with this virus, I must have been tested for it at some point prior to being told that I was infected with the same. This test was carried out without my knowledge and therefore without my consent.

15. My medical records state indicate that I was tested for HIV in 1990; the results of the test were negative. I was not told about this test which was carried out without my knowledge and therefore without my consent.

16. I was treated with Factor IX concentrates without being advised about the risk of infection from use of the same. I was therefore treated without my knowledge and impliedly without my consent.

17. As far as I am aware I was not used for the purposes of research. However, I think that I had a liver biopsy as a young teen. I am not sure whether this was for voluntary research purposes or whether there was another reason why I had this done or whether I had been asked to do it for research purposes.

Section 5. Impact

18.I have a multitude of physical health problems arising from both my Haemophilia and Hepatitis C. These include, but are not limited to the following:

- a) Jaundice in 1979;
- b) Haemarthrosis affecting most of my joints. I have also suffered with numerous and very painful muscular bleeds necessitating hospital admissions;
- c) chronic osteoarthritis and arthritis to the extent that I am effectively crippled, have very limited mobility and suffer with severe pain on a daily basis;
- d) numerous tooth extractions;
- e) cervical lymphadenopathy which is a disease of the lymph nodes;
- f) left ankle cheilectomy and removal of osteophytes and joint washout in February 2006;
- g) upper GI endoscopy in July 2006 which led to the discovery of a hiatus hernia for which I take regular medication. I also have a rectus sheaf hernia;
- h) sleep apnoea. I have to use a CPAP machine to help me sleep. I have difficulty sleeping due to pain in my joints and being unable to get comfortable in bed. I am unable to sleep on my sides due to having broken both collar bones and both shoulders in RTA's and I have subsequently developed osteoarthritis in the shoulders. I am only able to sleep on my back and I wouldn't be able to do that without my CPAP machine as I stop breathing;

- i) triple right ankle fusion in 2018 which produced an outcome which the Senior Consultant said "*was excellent from a bone fusion perspective*". I was hoping that this would achieve increased mobility and a reduction in pain. However, following the operation I am experiencing a new and different type of pain which I am hoping will settle although I am dubious about the long term effect of this operation. This is worrying as I also require the procedure in my left ankle;
- j) I will also require a total knee replacement in my right knee due to chronic osteoarthritis. I also need keyhole surgery on my left knee due to a meniscus tear.

Hepatitis C Treatment and Depression

- 19. I underwent two courses of treatment in order to clear my Hepatitis C between 1997 and 1999. I initially underwent a course of Interferon and I then underwent a 12 month course of Alpha Interferon and Ribavirin.
- 20. I had to discontinue the first course in August 1997, as evidenced by my medical records, and therefore the first treatment was unsuccessful at clearing the virus.
- 21. Despite the fact that I endured horrific side effects during the first course of treatment (listed below), I was resolutely determined that I must press on and endure the second course as I knew that this was my best chance of clearing the virus.
- 22. I experienced the most horrendous side effects during both the first and second courses of treatment which culminated in a suicide attempt during the second course of treatment. My medical records confirm that the treatment caused me to suffer with severe depression, poor concentration, headaches, distortion of sleep pattern, flu like symptoms, loss of appetite, extreme weight

loss, fatigue, dry skin and alopecia. I looked gaunt, tired and was fading away.

23. I had never suffered with depression before undergoing the treatment. It was a complete shock to feel so low and I had to traverse a new and difficult path in this regard. Looking back, I do think that the suicide attempt was a cry for help because I did not take a sufficiently large overdose to kill myself.

24. I was working as an IT consultant during my treatment and I remember falling asleep at my desk due to the incessant tiredness caused by the treatment. I used to ride my motorbike to and from work and, on 24th June 1999, I fell off my bike due to the extreme fatigue I was suffering as a result of the treatment. I was very lucky to escape serious injury. This accident is documented in my medical records.

25. Despite the severity of the side effects, I managed to complete the full course of the second treatment and I was declared clear of the virus towards the end of 1999/beginning of 2000.

26. The current depression started about 3 to 4 years ago due to chronic pain as a result of my osteoarthritis in my ankles and knees which resulted in my becoming badly disabled and on really bad days, being unable to walk at all.

27. Currently, I am particularly struggling with the enforced isolation as a result of Covid 19. I just have to take things on a day-by-day basis.

28. I also started to notice memory problems in my late teens and early twenties which have gradually got worse over the years. I am unsure if this is related to the Hepatitis C virus. For example; I used to be a hairdresser in my late teens/early twenties and I would recognise my regular clients in the street but couldn't remember their names.

Disclosure of Hepatitis C

29. I have always been very open with people about my infection. I told friends and work colleagues and, in the main, everyone has been very understanding.

30. I actually had more of a problem in relation to AIDS, despite the fact that I have never been HIV positive. During the 1980s when AIDS scaremongering was at its worst I felt that I could not even disclose the fact that I was a Haemophiliac because everyone assumed that all Haemophiliacs had AIDS. I therefore downplayed my Haemophilia during this time.

Employment

31. I managed to continue in my IT consultant role during my Hepatitis C treatment. The company I worked for were absolutely brilliant and let me have time off when I was really ill as a result of the side effects of the treatment.

32. I used to manage my role in IT by working from home a lot which afforded me a degree of flexibility thus allowing me to manage my health needs. I always hit my targets, produced high quality work and received no negative feedback or complaints. However, in 2017 the company decided that my role would now require more of an office presence. Due to my health, I was unable to fulfil this new role and have therefore been unemployed since 2017. I am actually currently covered by the company's group income protection scheme and am not therefore claiming sickness benefits.

Section 6. Treatment/care/support

33. As far as I can recall I was not treated in an unfavourable way by clinicians or dentists as a result of my infections. Furthermore, I cannot recall any incidences of being refused treatment.

34. I have not been offered counselling or psychological support in direct consequence of my infections. However, the Haematology Department at the MRI put me in touch with a social worker who helped me claim the higher rate component of Disability Living Allowance (DLA) which I was entitled to after starting treatment for Hepatitis C. During the process of applying, I received a "*type of counselling*" from the social worker.

Section 7. Financial Assistance

35. I received the Stage 1 Payment of £20,000 from the Skipton Fund (SF) in 2004.

36. I was aware that the SF offered grants and the like but I did not need anything so I did not apply.

37. I now receive a monthly income from EIBSS together with the annual winter fuel payment.

Section 8. Other Issues

38. I want to understand why the UK Government sourced, imported and used contaminated blood and why clinicians delayed for so long before telling me that I had been infected with Hepatitis C and never told me that I had Hepatitis B.

39. Mine and others' lives were treated like a game of "*Russian roulette*" and I feel very bitter about what happened to me. It's as though life is considered to be worth so little by the people responsible for using contaminated blood products.

40. I want those persons who are responsible for this scandal brought to account.

41. Sufferers need to be awarded due and proper compensation.

Anonymity

42. I do not wish to apply for anonymity and, due to my poor physical and mental health, I am unable to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

GRO-C

Dated.....

13/05/20