

Witness Name: ALAN GARNER

Statement No: WITN2750001

Exhibits: 0

Dated: APRIL 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ALAN GARNER

I, ALAN GARNER, will say as follows:-

Section 1. Introduction

1. My name is Alan Garner. I was born on 1941 and I live at
 Nottinghamshire I have
been married for 53 years and I have two children aged 45 and 43.

This witness statement has been prepared without the benefit of access to my full medical records. I do have a limited number of records from 1979 onwards.

Section 2. How infected

2. I have mild haemophilia A with a clotting factor of 25% at the time of infection. Clotting levels can increase over time and my levels are now in the low normal range.
3. I am infected with the Hepatitis C Virus (HCV) from Factor VIII (FVIII) concentrate.

4. I was treated at the Sheffield Haemophilia Centre at the Royal Hallamshire Hospital, Sheffield under the care of Professor Preston and Professor Makris, Professor Makris exclusively from the 1980s when Professor Preston retired.
5. As a mild haemophiliac I had very little (hardly any) treatment. I had cryoprecipitate at Sheffield and a dose of the FVIII product BPL on just one occasion at the Queens Medical Centre, Nottingham in 1979. On that occasion the ambulance was diverted from Sheffield to Nottingham after an accident wherein I had put my hand through a caravan window. It was never confirmed to me but it is my belief that I became infected from the BPL treatment that I had in 1979 at Queens, Nottingham, 1979 being the only year I have a record for.
6. I was informed by Professor Makris in or around 1988 that I was infected with HCV from FVIII. He said that there was 'a problem' and that I 'had been infected with Hepatitis C but fortunately I had not been infected with HIV'. I went to the Haemophilia Centre regularly. There was a nice family atmosphere there. Everyone knew each other. Dr Makris was a nice man and we got on well. Sheffield were at the forefront of finding a cure for HCV. I was not unhappy about how I was told but, in retrospect, the news of my diagnosis could have been better delivered to me and better information provided.
7. I was told that they were trialling the drug Interferon as a possible cure and I could be placed on the trial if I so wished. I was informed that the virus could cause serious liver damage and could substantially shorten my life. I do not recall being told how to manage the infection. Little was said about the risk of the spread of infection to others and I feel this should have been stressed. I researched the virus myself. I found out that it could be transmitted sexually and through blood contact. After that I was careful at home and, for example, made sure my toothbrush was kept away from the rest of the family. I spent the rest of my life being worried about my wife and children becoming infected.

8. I do not know when they were aware that I had the infection. I was not told.

Section 3. Other Infections

9. I do not believe I received any other infections besides HCV.

Section 4. Consent

10. When I was informed that I had HCV I had no idea that I had been tested. Since I had no idea that I had been tested I could not have given my consent.

11. In the first stages I was not given adequate or full information.

12. I was offered the opportunity to join the Interferon trial in or around 1989 so the research element was explained to me. In some ways I was a guinea pig but I was grateful for being given the opportunity to try and cure the infection.

Section 5. Impact of the Infection

13. Living with the realisation that your liver has been damaged and that your life could be dramatically shortened plays on your mind, particularly when you have a family to support. You also worry that you might accidentally infect others, particularly close family.

14. I suffer from serious liver damage as a result of HCV. I have scarring of the liver. It has seriously impacted on my energy and vitality levels.

15. In around 1989, I had my first treatment with Interferon which failed to clear the virus. As a condition of entering the study, I agreed to have two liver biopsies, one before and one after the treatment to ascertain the impact of the interferon. These biopsies were not too pleasant and carried a risk in themselves.

16. Around 18 months later, I was referred to the liver unit at the Royal Free Hospital in London. They recommended a double dose of Interferon. This, again, failed to clear the virus. The side effects were debilitating. I felt tired and lifeless and it became difficult to do anything energetic. My oxygen levels in my blood also dramatically dropped.
17. When Ribavirin came on the scene I was given it combined with Interferon. I was taken off the drugs after 12 weeks because the viral load had not fallen sufficiently to make success likely.
18. When Telaprevir came on the market (around 5 years ago) I was given that drug along with Interferon and Ribavirin. Since I had failed previous treatment I needed to be on these drugs for a year. This combination finally cleared the virus.
19. I did have problems with nerve damage to the hands and feet which the neurologist suggested had been caused by the various drugs.
20. I feel that I coped well with the four separate treatments that I received. I did feel depressed at times and questioned whether it was all worth it. When I was on the triple combination therapy, which was very gruelling, I had to fill in a form to say whether I felt suicidal which was a worry in itself.
21. The four treatments that I received were progressively debilitating. The triple combination therapy which lasted a year reduced me to be only able to walk a short distance. My red blood cell count was so low that I was close to being taken off the treatment for safety reasons. I also had to have ECG tests every few weeks to check my heart. I developed serious skin reactions which were very uncomfortable. I was unable to eat properly as I felt sick all the time. I also found it very difficult to eat fat rich foods which were necessary for the drug Telaprevir to be effective. I lost one and a half stone in weight.

22. There is a stigma associated with being HCV positive. It plays a part in all sorts of decisions you make with regard to the future. Having to declare that you were HCV positive when I had dental and medical treatment left me with the worry that others may be making judgements about me. I also felt the need to protect them.
23. The impact on my private, social and family life was that I have always felt the need to be open about my status as a warning in terms of accidents relating to blood spills. This carries with it the fear that some people may be prejudiced and make judgements. At home I worried about infecting my family.
24. I have never experience any outwards examples of stigma but I nevertheless worried that it may be there in the background of the minds of friends and colleagues. Some people were under the impression that you only had HCV if you are homosexual or a drug user, both regarded with negative connotations.
25. The physical effects of having HCV and the clearing treatments made work much more difficult and tiring. This has made it difficult for me to pursue promotion and more demanding roles. When I got the opportunity to take early retirement from teaching at the age of 50, I took it. I made the decision based on the premise that my prospects for a long life were not good and I wanted to do the things that were important to me and my family. This came at a price as it reduced my long term pension prospects.
26. Being HCV positive was a major factor in taking my early retirement. This caused financial difficulties as I had a daughter at school and a son at university and I could not give them the support that I would have liked. I have always been a saver but I lost the motivation and ability to save any more for later life.
27. The impact on my family is more difficult for me to assess. I hope that my positive attitude reduced their concerns but they must have worried about

whether they were about to lose a dad or husband in the near future. I explained my infected status to my children so they were aware that they may not have a father to support them in the future. My family have been very supportive throughout.

Section 6. Treatment/care/support

28. Being at the forefront of finding a cure for HCV, all the treatment options were made available to me.

29. I was never offered counselling but I feel that I was coping well with the situation. I might have needed counselling had I developed liver cancer. The Sheffield Haemophilia centre had a wonderful Sister who looked after haemophiliacs. Joy Farnsworth gave me all the support that I needed and helped me through difficult times with the treatments.

Section 7. Financial Assistance

30. In 2004 I found out about the various Trusts through the Sheffield Haemophilia Centre. I received a Stage 1 lump sum payment of £20,000 from the Skipton Fund on 2nd November 2004.

31. The Caxton Foundation contacted me in 2014 to say that I was eligible for the winter fuel payment. I received this until it was incorporated into the new government scheme introduced in 2016 or 2017. I am currently in receipt of this payment. I was not eligible for others benefits as they were means tested and our (my wife and I) combined pensions and state pension took us beyond the limit.

32. The process of applying was straight forward. I experienced no issues other than the issue of the payments being means tested.

33. I feel very strongly that having HCV seriously impacted my financial situation. It reduced my earning power and was instrumental in me retiring early and has significantly limited my pension pot. Because I have been frugal and my wife has a pension, I have been excluded from many of the means tested payments I believe I am entitled to. I know that I am luckier than many others but because I have survived HCV and am in receipt of an occupational pension, I am let down by the system.

Section 8. Other Issues

34. I contacted my local MP as long ago as 1995 to ask for help raising the issue of contaminated blood and financial compensation. I have been instrumental in eliciting and support of my MP, Paddy Tipping, who has, in turn, offered his support to the Haemophilia Society and the campaign for justice.

Anonymity, disclosure and redaction

35. I have no concerns with regard to anonymity. I understand this statement will be published and disclosed as part of the Inquiry. I do not wish to give oral evidence but if the Inquiry would benefit from hearing oral evidence from me I would attend.

Statement of Truth

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

Signed ..

GRO-C

Dated ..

April 20th 2018.