

28 NOV 2018

Witness Name: SIMON CLIFFORD
BIRKBECK

Statement No.: WITN0058001

Exhibits:

Dated: 20 November 2018

INFECTED BLOOD INQUIRY

GRO-C

FIRST WRITTEN STATEMENT OF SIMON CLIFFORD BIRKBECK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26th October 2018.

I, Simon Clifford Birkbeck, will say as follows: -

1. Introduction

1. My name is Simon Clifford Birkbeck. My date of birth and address are known to the Inquiry. I am now retired, as I took early retirement in 2017 at the age of 60. I am married with three adult children. I intend to speak about my infection with Hepatitis C as the result of receiving a Factor VIII blood clotting treatment. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on myself and my family and our lives together.

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2. How Infected

2. *Establish in as much detail as you are able to, how the witness was infected by infected blood products. In particular please detail:*

- a. I am a Haemophiliac affected by Haemophilia A. This was diagnosed when I was a child following a bleeding incident. The severity is classed as mild, so the number of bleeding incidents that I have experienced, requiring treatment or prevention, is relatively few.
- b. I lived and worked in London in the 1980s, and frequently cycled to and from work in central London. On a wet morning, a motorist did a three-point turn in front of me and I was unable to stop before hitting his off-side. My upper arm impacted the roof of the car and I developed a haematoma as a result. This was the first accident that I had sustained as a haemophiliac which caused a bleed.
- c. I was worried about the swelling of my arm, so after arrival at work I went to the nearest hospital seeking treatment. I had not been to this hospital before. The hospital was the Middlesex Hospital, which was in the Fitzrovia area of the West End. I went to the Accident and Emergency Department. I do not know the names of any of the doctors or other medical staff who treated me. I was given Factor VIII, which successfully stopped the bleeding problem. I do not recall any details now of any follow up treatment. As far as I was concerned at the time the incident and its treatment were over. I was not (to my recollection) ever given any advice as to there being any risk of infection from blood products. I think I was registered at the hospital following this as a Haemophiliac.
- d. I made no note of the date of this incident nor of the treatment afterwards. It was definitely after 1982 and before 1986. I had no further need for blood products (or other treatment of bleeding) following this until well after we moved to Bristol in 1990. I was

married in 1987. When we moved to Bristol, I registered myself at the Haemophilia Centre of the Bristol Royal Infirmary (BRI).

At the BRI, I was called in occasionally for routine blood tests. On more than one occasion I can recall being vaccinated against either Hepatitis A or Hepatitis B.

I can recall first being told that I had contracted Hepatitis C (HCV). I had clearly been tested but I am fairly sure that nobody told me in advance that they were testing me for HCV. I was told by the Haemophilia nurse at the time that I had HCV. Again, I am afraid that I did not keep a record of the date of this news. It would however have been sometime in the mid-1990s as I was undergoing subsequent treatment in and around 1997/1998.

I had not heard of Hepatitis C. The symptoms were not really noticeable. I was given some information on the possible outcomes if the infection was left to run its course. I was not offered any emotional or counselling support. In retrospect it seemed surprising that such a long period had elapsed since the original infection. It was at about that time that news of the infected blood tragedy started to reach newspaper headlines. I recall reading a headline on someone else's paper (on the train) and this shocked me. I don't think I had really understood the significance or the seriousness of the infection.

Looking back now, I believe I should have been told earlier about the risks. I believe that I should at least have been asked before they tested my blood and told about the infected blood scandal.

I am not sure if they adequately explained the risks of sexual transmission to my wife. By this stage we had been married several years and we had conceived three children.

3. Other Infections

3. I have been advised that there is a small risk of my developing CJD from the infected blood product.

4. Consent

4. I believe that I had my blood tested for HCV (and presumably HIV):
 - a. without my knowledge, and
 - b. without being given adequate or full information

5. Impact

5. *Obtain from the witness, in as much detail as you are able,*
 - a. I was surprised that the HCV infection appeared to have relatively few physical symptoms at that early stage. I was led to believe, however, that it was likely to develop and lead to cirrhosis of the liver and possibly ultimately liver cancer. I was given no emotional or counselling support so I was left to proceed with the recommended treatment.
It was likely that I would not be able to take out life insurance. Fortunately, my employer had a blanket policy for all employees.
 - b. The risk of CJD has led to complications in the investigations of my colon. In 2006, I developed Ulcerative Colitis and am receiving regular treatment for that. It has been recommended that I should have a colonoscopy every year or two. When they undertake a colonoscopy, they need to use a specially dedicated scope to avoid infecting other

patients with CJD. I am led to believe that the scope cannot be sterilised from possible CJD contamination. On one recent occasion, my colonoscopy had to be cancelled at the very last moment, (I was ready and prepared at hospital), as the dedicated scope was not prepared and ready. This is a complication that I could well do without.

c. At the BRI, in the mid to late 1990s, it was recommended that I should have a liver biopsy to check for damage arising from the HCV. I was admitted to hospital for this procedure. My recollection now is that I actually had two such biopsies. I do not now recall being given much feedback from these investigations and tests.

Subsequent to this, I was put on a treatment programme comprising several months of injections of Interferon. My recollection is that I had to self-inject three times a week. The Interferon had a side effect rather like influenza. I was advised to inject in the evening so that the side effects would be mainly at night. Despite this treatment, I carried on working. I was tested for the HCV virus on several occasions and I was still positive. I believe I was on this treatment for at least three months – possibly six.

I was then told that there was a trial treatment available which continued the dosage of Interferon but also included a drug called Ribavirin. It was explained to me that initial indications suggested that the likelihood of clearing the virus was improved by this combination treatment. I was also advised that the drug might have a negative impact on any child conceived at this time – but we had already decided by this stage that we wouldn't have further children.

I agreed to this new treatment. I don't recall how long I was on this, but my estimate is in the region of another three months. I recall being on holiday in the Lake District with my family in 1998 and being very weak and not really able to enjoy the break. Again, I managed to keep

on working – but the effects of the treatment were that I felt permanently drained, weak and tired.

d. I did not experience any difficulties or obstacles in accessing the treatments. The physical effects were demanding, but again I do not recall any formal emotional or mental support being provided.

e. I was very pleased to learn that the HCV tests were now proving negative. The BRI continued with blood tests periodically over the next year or more until they were satisfied that I had cleared the virus.

f. It was the Interferon and Ribavirin treatment that reduced my energy and fitness levels such that it was hard work bringing up a young family. They were in the approximate age range of 6 to 11 whilst I had the treatment.

I never disclosed to other than close friends and family the infection or its treatment. That way I avoided any stigma associated with the infection. It did mean however that I kept working throughout this period and took very little time off sick.

6. Treatment/Care/Support

6. I did not have difficulties or obstacles in obtaining medical treatment in consequence of being infected with HCV. There was however no mental support provided.

No counselling or psychological support has ever been made available to myself in consequence of being infected as described.

7. Financial Assistance

7. I was in receipt of a Stage 1 Lump Sum from the Skipton Fund.
- a. I do not now recall how I found out that financial assistance was available.
 - b. A lump sum of £20,000 (I believe) was paid by the Skipton Fund. I do not know exactly when this was paid and do not recall the exact process of application. I think however that the Skipton Fund were quite proactive in the process.
 - c. I subsequently (but much later) discovered that I was entitled to free prescriptions. I remember being telephoned by the Skipton Fund and told about this. This was sometime in the last ten years.
 - d. I am now in receipt of regular monthly payments from the NHS Business Service Authority (NHSBSA) (which took over the role of the Skipton Fund).

I have recently learned that Income Top Up Discretionary Support Payments are also available. I have applied for these earlier this year and am now in receipt of these payments. I do not know if these were available before the NHS BSA took over the role of the Skipton Fund

8. Other Issues

I do not have any documents or medical records relating to my infection or its subsequent treatment. I was until 2014 registered at the Haemophilia Centre at the BRI. In 2014 we moved to North Yorkshire.

Statement of Truth

