

ANONYMOUS



Witness Name:

Statement No.: WITN0015001

Exhibits: WITN0015002

Dated: 2 October 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 September 2018.

I, , will say as follows: -

Introduction

1. My name, date of birth and address are known to the Inquiry. I am a single man with no siblings. My father died in 2008 and my mother in 2017. I intend to speak about my personal experiences of having been given infected blood products. In particular, the nature of the infection, how it affected me, the treatment I received for it and the impact the infection had on my life.

Infected Blood Inquiry

Fleetbank House, 1st Floor, 2-6 Salisbury Square, London EC4Y 8AE

contact@infectedbloodinquiry.org.uk

Freephone 08081691377

ANONYMOUS

How Infected

2. My severe Haemophilia B (formerly known as Christmas Disease) was diagnosed after I was circumcised as a baby. Because of my fragility I did not go to school until I was 13.
 - 2.1. I was treated from birth until 1979 at the Manchester Royal Infirmary where I received blood transfusions, plasma, cryoprecipitate and in 1973 the first of the concentrates.
 - 2.2. I know that some of the concentrates I received were sourced from the USA but I cannot recall the date.
 - 2.3. Since 1980 I have been under the care of the Royal Free Hospital.
 - 2.4. In January 1991, I was informed by letter that I had tested positive for Hepatitis C (HCV) in November 1990. A copy of the letter is exhibited to my statement at **W0015-01**. I cannot say where I was infected with HCV.
 - 2.5. Little or no advice was given by either hospital on the risks associated with blood products.
 - 2.6. In 1975 ITV's World in Action alerted me to the danger.
 - 2.7. Around 1992 I was given an appointment with one of the country's leading hepatologists. Flanked by a panel of departmental staff he told me that the prognosis was bleak and that I should seriously consider taking Ribavirin, the only available drug for the treatment of HCV. Since the drug had a poor success rate and caused very unpleasant side effects I said that I would prefer to wait for a better treatment. I left the meeting in a very anxious state. My next step was to explore alternative medicine. I tried Traditional Chinese Herbal Medicine and found it helpful.

ANONYMOUS

- 2.8. The hospital gave me no information about managing the infection and so I had to do my own research in libraries. The Haemophilia Society, however, did provide useful information and a contact telephone number. In an effort to improve my knowledge of alternative therapies I attended courses in Herbal Medicine and Nutritional Medicine. On the basis of what I learned I adopted a regimen of food supplements, including Milk Thistle, and modified my diet. I believe that this approach helped to prevent further damage to my liver and the progression to cirrhosis.

Other Infections

3. In the mid-seventies I was hospitalised with acute hepatitis. I was given little specific information at the time but many years later I was told that I had been infected with HBV and had cleared the virus.

Consent

4. I must have been tested without my knowledge. Since my main concern was diagnosis and since consent was regarded differently at the time I did not give much thought to the matter.

Impact

5. For 24 years I suffered from chronic fatigue, "brain fog", chronic migraines, recurrent 'flu-like' symptoms, irregular heart rhythm and a general malaise. In 1994 I had to leave my job owing to the increasing stress of trying to cope with the illness. I felt so unwell that I had to give up all my evening classes and activities in art and singing. My social life, too, came to a halt and I became isolated and almost hermitical. I felt like a social pariah and at times wondered whether I could be a public danger: I was constantly anxious about the possibility of transmitting the infection to others. The irregular heart rhythm gradually worsened until I collapsed in 2017 and was diagnosed in A&E with a heart condition, atrial fibrillation. In short, the

ANONYMOUS

impact of being infected with HCV has been to blight over one third of my life and to leave all my hopes and aspirations in ruins.

Treatment/Care/Support

6. In January 2017 after a long wait for it to become available in the NHS I was treated with the latest double-drug therapy, Viekirax and Exviera, and since completing the course in April 2017 there has been no trace of HCV. I am pleased to report that there were no noticeable side-effects or complications. After treatment my symptoms improved and my energy levels have risen. I am now trying, in old age, to resume painting again.
- 6.1. I have found dental care very difficult to obtain. For almost 4 months I have been waiting for a referral to be approved. Two referrals have been rejected and I am still waiting for the third to be processed through the local triage system. I have been given contradictory reasons for the rejections. I do not know whether the difficulty relates to my haemophilia, my history of HCV infection or both.
- 6.2. I cannot recall ever being offered any psychological help but I would probably have declined any such offer.

Financial Assistance

7. I received an ex-gratis payment of £20,000 from the Skipton Fund in 2004. If it were not for savings and prudent budgeting I would have experienced some difficulty in managing after I stopped working. Since I did not develop cirrhosis I did not receive the next payment.
- 7.1. Presently I receive £333 monthly pension from EIBSS, which is helpful. Payments began in 2016.
- 7.2. The process of applying for assistance was smooth for me.

ANONYMOUS

Other Issues

8. I took up the issue of justice for victims of contaminated blood products with two local MPs. Dr Vince Cable was helpful and spoke in the Commons about the matter.

8.1. I heard that some of my medical records have gone missing.

8.2. I would like my identity to remain anonymous.

Statement of Truth

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

Signed: GRO-B

Dated *5/10/2018*