Witness Name: David Lowles
Statement No: WTN1356001
Exhibits: 0
Dated: April 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DAVID LOWLES

I, David Lowles, will say as follows:-

Section 1. Introduction

1. My full name is David Anthony Lowles. I was born on GRO-C 1965 and I live at GRO-C Leicestershire GRO-C with my wife, Donna.

2. I was infected with the Hepatitis C Virus (HCV) through contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. I have mild Haemophilia A, diagnosed in the mid 1970s. The diagnosis took a while in the making as they suspected Von Willebrand's Disease before I was identified as having mild haemophilia with a 7% blood clotting factor. I am

currently on DDAVP treatment and my blood clotting factor has been boosted to 45%.

5. I was treated at the Leicester Royal Infirmary (LRI) under the care of Dr Mitchell (now retired). I was treated with Factor VIII (FVIII) concentrate, always at hospital, as and when it was needed.

6. No advice was given to me or my parents about the risk of infection through contaminated FVIII concentrate.

7. In 1995 (when I had just turned 30 and recently married), my wife and I were told by one of the doctors (I do not recall his name) that I had hepatitis C. My memory is hazy and I do not remember being given very much (if any) information to help me to understand and/or manage the infection at that particular appointment. My wife is what I would describe as being emotionally strong and because of this, it was a little easier to bear. She attended appointments with me and became my rock.

8. I remember being told (around that time) that I had been infected with Non-A Non-B Hepatitis (NANB) through unheated/untreated FVIII concentrate. I was told not to let anyone touch my blood should I have an accident. In my mind, the biggest kick in the teeth that I was given then, was to be told that I must *not*, under any circumstances, drink alcohol. It took me some time to process that particular instruction as I enjoyed going out drinking with my friends. At subsequent appointments I was asked about my current alcohol intake.

9. Some years later, when I started to have a problem with my liver, I was reassured that the problem was nothing to do with my lifestyle and that they, the LRI, had given me the HCV infection and the HCV had caused the problem. Those reassurances put my mind at rest as I did kerb my alcohol intake and do not drink at all any more.

Section 3. Other Infections

10. In or around May 2004, I received a letter informing me that I was thought to have been at risk of exposure to vCJD.

Section 4. Consent

11. I was tested for hepatitis without consent because I didn't know about the test. Bloods were taken from me on a regular basis without me being told that the samples would be used to test for infection. After I was informed that I had HCV (then NANB) I was tested for HIV on a fairly regular basis and I knew about it. It is quite possible that I was also tested for HIV without my knowledge when I was tested for hepatitis.

Section 5. Impact of the Infection

12. My physical health has been hugely impacted since from around the early 2000s. The damage to my liver caused by having HCV has resulted in me suffering with splenomegaly, thrombocytopenia and portal hypertension.

13. These very serious medical conditions are complicated by the subsequent development (in 2007) of oesophageal varices that need monitoring on an ongoing basis. I am currently taking Propranolol to reduce my heart rate to help with the portal hypertension and will continue to take this medication for the rest of my life.

14. In March 2009 I had a brain haemorrhage and mini stroke followed by a craniotomy. I had to have physiotherapy to regain the use of my right hand. I have lost 10% of my memory since the operation. It will not be regained.

15. I struggled in applying for jobs and securing work. As soon as I mentioned I had HCV, the interview would be over with words like 'OK I will get back to you' and the 'getting back to me' never happened. The rejection worsened

when I had to mention a brain haemorrhage on top of having HCV. I had decent jobs previously to include driving a bus, and driving a Class 2 Truck. I am now viewed as high risk and have to take whatever work I can get on a much lower wage. I am currently working as a van driver earning the National Minimum Wage.

16. I have definitely been financially impacted. The DVLA were notified when I had the brain haemorrhage and craniotomy. My driving licence was revoked for 14 months. I was unable to go anywhere on my own and was completely reliant upon my wife. At the time I was working as a class 2 delivery driver for a vending machine installation company. I was out of work for 6 months. I returned to work after that doing odd jobs in the warehouse. My wife had to drive me to and from work every day as well as hold down her own job. She was in effect my carer as I relied upon her for everything. She, in turn, was exhausted, GRO-C, GRO-C GRO-C. I felt like "It was all my fault that this had happened". My wife and I were together for a long time before we married in 1994. She has been on this journey with me. It has been massive for both of us. I would not have got by without her.

17. I finally cleared HCV in 2016 but I still have to have ultrasound scans every 6 months to monitor the liver cirrhosis and check for signs of cancer. Because of the varices I have to have endoscopies. I have had bone scans to check for brittle bones, I have flu jabs and I attend at stroke clinics. These appointments are difficult for me as I need time off work to go. Having HCV from contaminated blood has changed my entire way of life.

18. The memory loss from the intracranial bleed I had in 2009 is particularly debilitating for me and with the brain fog, things have got worse. My wife describes me as being like a five year old. I can load a dishwasher and add the tablet and will walk off without turning it on. I can put something in the oven and forget that I have put something in in the first place.

19. The worst of it is the behaviour of people that don't know what I've gone through or that they just don't want to understand. The stigma of having Hep C makes me feel like a "Leper". I found that people are afraid of what they don't understand and can be genuinely cruel. I forget things at work and have been called 'stupid'. Some times it is just banter and I am known as a bit of a joker myself but I have had to explain in detail what I have gone through before people come to terms with it. Even then, the stigma is hard to shift. Every time I start a new job I have to go through the same explanation and the same trauma not knowing if I will be accepted. Life can be awkward that way sometimes.

Section 6. Treatment/care/support

20. I had three attempts at clearing the virus. The first attempt was a combination Ribavirin and Pegylated-Interferon treatment that I had to put together myself. I started the treatment towards the end of 2001 and I was supposed to be on it for a year. The treatment totally changed me and I had to give up on it after three months. I suffered with flu like symptoms and I lost my appetite to the extent that I couldn't even bear the smell of foods I previously loved. The main problem was my mood change. I was aggressive, tearful and irritable. In short, I was a pig to know and if I could have put myself into a box and turned off the light I would have done so.

21. My second attempt at clearing the virus was a premade treatment through the Queens Medical Centre in Nottingham. My wife did the injections and I was better able to tolerate it although it wasn't pleasant. I completed the whole 48 weeks of treatment in April 2005 and it was at first thought to have been successful. It was a real blow to me to learn that the virus had returned and all that treatment was for nothing. I am HCV genotype 4 which is hard to clear. There was a lot of talk about possible treatments that I could trial but nothing actually happened for a long time and until I was put on to the 12 week Harvoni trial in 2016. That third attempt was successful.

22. Counselling or psychological support was never offered to me. Because of my memory issues I very much doubt that it would have been of any benefit to me.

Section 7. Financial Assistance

23. I have had the Stage 1 and the Stage 2 Skipton payments (because of the liver cirrhosis). I have received monthly financial assistance from The Skipton Fund and am currently receiving through EIBSS. I have had no issues and the support now in place is available to me if I need it, e.g. counselling, free prescriptions, and a list of other benefits.

Section 8. Other Issues

24. I would like an apology for what has happened and, at the very least, an acknowledgement that this was done to me. I want to know why it happened and whether it was sourced from America and used on us without testing just to see what would happen to us. This is NOT about financial gain, but a compensation payment for the trauma, stigma and the treatment I am still receiving would be beneficial.

25. I would like to add, that the treatment I have received from the NHS has been phenomenal and they have treated me with the utmost respect and dignity. Although this has happened to me, I still have a positive attitude to life, and with the support of my wife, I will continue to do so.

26. Since all this began, I have had a lot of hospital visits, which have been financially draining, but thanks to monthly payments from the EIBSS, it has made life more bearable and given us a light at the end of the tunnel. I now feel like they are righting the wrongs, which I am extremely grateful.

Anonymity

27. No anonymity is required.

Statement of Truth

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

Signed GRO-C

Dated 19th April 2020.