Witness Name: Elizabeth Emily Lamch Statement No. WITN4077001 Dated:6th August 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ELIZABETH EMILY LAMCH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13th March 2020. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Elizabeth Emily Lamch, will say as follows:-

1. Introduction

- My name is Elizabeth Emily Lamch. My date of birth is **GRO-C** 1990 and my address is known to the Inquiry. I live with my partner, Kirk Ellis, and our young son, **GRO-C**. We began our relationship in 2012.
- 2. Kirk became infected with hepatitis C as a result of infected blood and blood products and has made his own statement to the Inquiry (WITN2331).

2. How Affected

- Kirk was diagnosed with haemophilia as a baby, and was given Factor VIII treatment in the 1980's. This treatment infected him with hepatitis C.
- 2. For as long as I have known Kirk, which is approximately eight years, he has always been the type of man to just get on with things. He isn't embarrassed about his hepatitis, but he is infuriated that this scandal has happened.
- Kirk received treatment with Epclusa and Ribavirin in December 2016. It lasted six months and he is now undetected for hepatitis C. Kirk is however, still struggling with the 'after-effects' of the treatment which include depression and outbursts of angry anxiety.
- 4. He has moderate haemophilia A and takes prophylaxis treatment of Factor VIII every few days to prevent bleeds. Sometimes, if he has an accident and needs more treatment, he will attend at the University Hospital of Wales, Heath Park, Cardiff (UHW).
- 5. In 1981 when Kirk was a young child, his parents were told by GRO-D that he had severe haemophilia and would be treated with Factor VIII whenever he had an accident. He received this treatment at the UHW. Kirk believes that it was during this time he became infected with hepatitis C.
- 6. My understanding is that Kirk's mother asked for further tests to be performed because she considered Kirk's symptoms not to be the same as those with severe haemophilia, and she was unconvinced that Kirk was a severe haemophiliac. The tests results confirmed that Kirk was, in fact, a moderate haemophiliac.
- 7. Kirk was 11 years old when his mother was informed that he had become infected with hepatitis C. However, I believe he was not actually told about his infection until he was 16. He recalls it being a worrying time, as he was starting to drink alcohol and become sexually active.

3. Other Infections

1. I am aware that Kirk found out that he had been exposed to vCJD but I have no further information about that.

4. Consent

1. It is my belief that Kirk was treated without his parents' full knowledge of the risks involved with the Factor VIII treatment. When he had blood tests his parents did not really know what they were testing for. My opinion is that Kirk was used as a guinea pig, to see what the treatments would actually do, and to find out if young children could fight the virus on their own. Kirk's parents being told he was a severe haemophiliac, and then being told he was moderate makes me think this. Maybe his mother would not have let them use the Factor VIII treatment so quickly if she had known he only had moderate haemophilia.

5. Impact

- 1. Kirk and I started our relationship in 2012. He has always been open and honest with me about his haemophilia and hepatitis C. At first, Kirk thought he could not be sexually active without protection, and that he could not have children because of the virus. I researched this and found that he could do those things without the risk of me becoming infected. I think that maybe Kirk was a bit embarrassed to ask anyone about these types of things. This was the start of an emotional rollercoaster for us both.
- 2. We moved in together in June 2015. At this time, Kirk was told that he wasn't allowed treatment for his hepatitis C as he didn't come under the catchment area for the UHW to provide this. He was on new antiviral hepatitis C drugs at that time. As Kirk had always been treated at the UHW we both found this extremely frustrating, especially as it was at this hospital that he had become infected. It seemed a bit of 'a postcode lottery'.

- It wasn't until a year later, in 2016 when funding became available, that Kirk started his treatment of Epclusa and Ribavirin. Mr. Brendon Healey at the UHW was his Consultant at that time.
- 4. The side effects from the first lot of treatment were so bad that Kirk had to stop taking it. He suffered from extreme fatigue, depression and anxiety.
- 5. In 2016 I found out I was pregnant with **GRO-C**, which unfortunately added extra pressure onto Kirk. He felt the need to provide for his family, but the treatment made him feel so ill that he just couldn't continue to work and take the treatment. Kirk was unaware at this time that he had cirrhosis of the liver resulting from the hepatitis infection, otherwise he would never have decided to stop taking the treatment and I wouldn't have let him.
- 6. At that time were making life changing decisions, such as starting a family. We wanted a child together, but I can honestly say, that if we had known that Kirk had cirrhosis, we most certainly would not have made the decision at that time. We would have waited until Kirk was better. I know this still infuriates him. The pressure of taking the treatment and having a young son was extremely stressful on us all. Saving money for our unborn son was the most important thing to Kirk.
- 7. After GRO-C was born in GRO-C 2016, Kirk was asked to go back on the Epclusa and Ribavirin treatment by Mr. Healey as soon as possible. He told him the cirrhosis was getting worse. This was the first time Kirk had ever been aware that he even had cirrhosis and believes that Mr. Healey was only compelled to tell him then, because Kirk wanted to postpone the treatment for a further period of time.
- 8. Kirk asked for further financial help from the Skipton support scheme, having previously received a stage 1 lump sum in 2004. He was granted £50,000 as a lump sum and £15,500 per year in monthly instalments. He then gave up work to be ready to start taking the new

anti-viral Epclusa and Ribavirin treatment but now knowing how seriously ill he actually was.

- 9. Kirk started taking the new treatment in December 2016 and completed it six months later. During this time his mental and physical health got worse. Since receiving the treatment for hepatitis his depression and anxiety have gone through the roof. He gets verbally abusive and frustrated at any little thing. He was not like this when we first got together. He gets so depressed that he doesn't want to get out of bed or shower or even leave the house. He has stopped doing the things he used to love and hasn't been able to return to work.
- 10.1 have also not been able to return to work as I am now Kirk's full- time carer. This was a big sacrifice for me, as I went from being an ambitious Sales Manager in retail, to having to care for Kirk and our son. I feel that if Kirk didn't have hepatitis C then we would both be going places in our chosen careers. Kirk as a Carpenter and me in retail management.
- 11. Being infected with hepatitis C has obviously impacted in Kirk's life massively. As I previously stated, Kirk has always been open and honest with me. He has told me how he never thought he could have a relationship or children in case he infected them too. He has told me that he 'went off the rails' drinking, **GRO-C** family members, all because he thought that one day this virus that he was given, was going to eventually kill him. He couldn't pursue his chosen career in carpentry as he didn't see the point in being passionate about something if he wasn't going to live long enough to see it through. He took the easy option and worked in factories. This has affected his mental state since he was 16 and carries on affecting him to this day.

6. Treatment/Care/Support

1. As Kirk thought life was not worth living, and no longer trusted doctors, he also didn't look after his haemophilia. This has led to

Kirk having to have many operations and has many more to come. These included: having his left leg straightened, right ankle fusion, left leg cartilage repair, left knee blood vessels cauterised, artery by-pass and an operation on his left hip. Some of these operations have been carried out more than once. The operations he will need in the future are: left ankle fusion, both hips replaced and left knee replacement.

7. Financial Assistance

12. In 2004 Kirk received a Stage 1 lump sum from the Skipton Fund but I'm not sure how much he received. In 2016 he asked for further financial help from the Skipton support scheme and received £50,000 in a lump sum and £15,500 in monthly instalments. He then gave up work to be ready to start taking the second round of treatment.

8. Other Issues

I do not wish to add anything to this section.

Statement of Truth

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

GRO-C Signed...

Dated 619/2020