

Witness Name: GRAHAM LAWTON

Statement No: WITN1341001

Exhibits: WITN1341002-5

Dated: NOVEMBER 2018

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF GRAHAM LAWTON

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I, GRAHAM LAWTON, will say as follows:-

#### Section 1. Introduction

1. My name is Graham Lawton. I was born on the **GRO-C** 1965 and I live at **GRO-C** **GRO-C** Lancashire **GRO-C** with my partner, Lynn. I have had a number of occupations. I am now retired on medical grounds. I have not worked since the 1990s.
2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

#### Section 2. How infected

3. I have mild Haemophilia A. I was diagnosed as a baby. My parents adopted me **GRO-C**. They had no prior awareness of any genetic issue from my biological parents.

4. I was treated at the Liverpool Haemophilia Department, I was initially under the care of Dr C Hay and then Dr M J Mackie.
5. I was treated with Cryoprecipitate and then a variety of Factor VIII (FVIII) products. Some (but not all) of the products are listed on my National Database record. I refer to Exhibit WITN1341002 being my UKHCDO Patient Annual Treatment Record and I refer to Exhibit WITN1341003 being an extract from my handwritten medical notes. The information pertaining to the period 1983 to 1987 is missing from both sources but it is clear from the handwritten document that I was treated within that period with Armour and 8Y FVIII. Moreover I believe was treated with FVIII product prior to 1981 (the first date listed by UKHCDO on their record). When I was about 14 or 15 years old I was given a lot of FVIII treatment for a serious injury to my arm sustained the school playground. I broke my arm jumping over a friend's wheelchair on an icy day. The bone broke right through the back of my arm.
6. I am co-infected with Human Immunodeficiency Virus (HIV) and Hepatitis C Virus (HCV).
7. My medical notes and records are missing and it is therefore unclear as to when I first tested positive for HIV and/or was told of the diagnosis. My own feeling (and that of my mother) is that I may well have been infected with HIV from contaminated blood received treating my arm injury. I was also at that time shown how to self administer the FVIII at home but I had a lot of FVIII at the hospital treating that injury.
8. I may have been as young as just 15 or 16 years old when I was told I had HIV. I cannot remember when it was for sure because of the passage of time but I was given a lift to my appointment by friends and I believe that I was driving myself once I was 17 years old. Dr Hay (at Liverpool at that time) said he was going to test me for HIV and then called me back for my results.
9. I refer to Exhibit WITN1341004 being documents identified within my medical notes and records and I refer to Exhibit WITN1341005 documents from

UKHCDO. The documents referred to under both Exhibits bear conflicting/inconsistent HIV diagnosis dates. There are also other documents within my medical notes and records that are vague on the date of diagnosis as detailed in my medical chronology at the end of this statement. Whatever age I was when I was told, I know that I did not have the emotional maturity to fully understand the enormity of the news.

10. I was on my own when I was told I was HIV positive. I simply said 'I had a feeling you were going to say that' as I had been called in. I asked what would happen next and Dr Hay said 'we don't do anything, we'll be in touch'. I don't remember much more or any advice as I had (mentally) switched off. I said to my friends 'yes I've got it' as I got back in the car to go home, probably the biggest mistake I could have made (to tell the others).

11. I remember having to go home and tell my parents. It was awful. My mum just broke down because she had more of an idea what HIV was.

12. I do not recollect any adequate information being provided to me and I should have been told sooner. Aside from being told that I was being tested for HIV by Dr Hay on just one occasion, I was never told of any testing. I refer again Exhibit WITN1341003. It would appear from that document that I had been tested for HIV as long ago as 31<sup>st</sup> January 1977. I am unclear of when the doctors found out I was HIV positive but as soon as they knew they should have communicated it to me.

13. I was not informed of any risks when I was first treated with FVIII. My parents were not advised of any risks. What I knew about HIV came from the media in the form of what I now regard as 'scaremongering'. I was only given adequate information about my diagnosis and treatment a lot later on.

14. I was told I had HCV in November 1992. I cannot remember who the consultant was. I cannot remember much about it because my attitude to life was not great at time. Having HIV occupied my thoughts and I was grieving for my wife. I had married my teenage sweetheart in 1990. Gina was my wife

for just seven weeks when she died that same year. Our son, Scott, was just eight months.

### **Section 3. Other Infections**

15. I received a letter relatively recently advising me that I may have also been exposed to risk of vCJD.

### **Section 4. Consent**

16. I believe that I was tested for a number of infections without my knowledge or consent. Whenever I had an appointment, the doctors or nurses would take several vials of my blood and say they were 'testing for inhibitors'.

17. I have never withheld my consent and it is likely that I would have consented to testing had I been told and given transparent information and advice. I do volunteer my blood for research, gene therapy and the like.

### **Section 5. Impact of the Infection**

18. I suffer with IBS caused by the HIV HAART medication. I have cirrhosis of the liver caused by HCV (Genotype 1B). My Fibroscan reading was 20.9 kPa on 13<sup>th</sup> March 2013 (around the time of my second attempt at clearing the virus, which proved successful).

19. My HIV treatment was difficult to get right in the early days. There was nothing consistent about the medication I was given. I suffered with tiredness, insomnia and had very bad night sweats to the extent I would need to take a shower in the middle of the night.

20. I have had two attempts at clearing HCV. The first treatment of Interferon injections and Ribavirin was in 2005 and lasted for thirteen months. It came with horrendous side effects. I could hardly get out of bed. I was horrifically

sick. I had nightmares every night without fail, in 'glorious' technicolour, mostly about Gina. I had night sweats and was exhausted and depressed. The second attempt in 2013 was a little better in terms of side effect but still bad in terms of nausea, insomnia and night sweats. I had a pen to inject my treatment over 12 months.

21. The stigma and the attitude of other people has been very difficult to deal with. As stated, I told my friends as soon as I was told I had HIV. The word soon spreads. I recall having a drink just after I was told at a pub run by my friend's girlfriend's parents. I looked back into the kitchen after he had collected our glasses and saw him drop my glass into the bin. He did the same with my next drink.

22. After Gina died, a close friend of hers, came 'gunning' for me, accusing me and telling others that I had infected and killed her with AIDs. That was not true. She died of an infection she picked up from a tooth abscess, that led to inflammation of the heart and nothing to do with HIV. My son was fostered by a friend because I was not in the right place psychologically to care for him.

23. A dentist I visited at Liverpool Hospital made me wait in a separate room. He then covered everything in plastic and he and his team put on plastic suits that completely covered them. I can laugh now but I have never felt so alienated in my whole life. I looked back when I left the room and saw them picking up the spray to clean the seat I had sat in.

24. **GRO-C** suffered from a **GRO-C** attributable in part to the worry and stress arising from what has happened to me. I now deny that I have HIV to friends and laugh it off as 'a mistake' by the medical profession. If someone asks I respond by saying "Do I look like I have HIV?" I have not told my son I have HIV because I can never find the right time.

25. When I left school I had a keen interest to join the ambulance service. I was accepted and then rejected when I informed them I had HIV. It was a big kick to me. My haemophilia was mild, it would not have stopped me from doing

that job. I could not even apply as a volunteer as a first responder. I could not join the Police or do anything else I wanted to.

26. Living with HIV and HCV is a death sentence. It changes your mind set. I was once informed (after first being told I could die imminently) that I could expect to be dead by thirty-five. I thought 'nuts to it'. I applied for credit cards and decided to spend and enjoy it. I ended up with £42,000 in debt, purely because I thought I was going to die. I cleared the debt with the money I received from the Skipton Fund. I believe I would otherwise have been on the property ladder.

### **Section 6. Treatment/care/support**

27. It took a while before I was given HIV treatment. I was initially told to wait until my condition got 'bad enough'. I felt like they were waiting for me to develop AIDs before helping me. On the whole however I would say that the hospital has been good in terms of discussion surrounding treatment. Patients are invited to meetings. I usually decline. I just say 'do what you need to, to keep me alive'. They can however be a little slow at looking at changing the drug regime.

28. The McFarlane Trust offered me counselling and I believe they would have funded it.

### **Section 7. Financial Assistance**

29. I received Stage 1 and Stage 2 payments from the Skipton Trust. Vanessa Martlow fought hard against the Skipton to ensure I got the Stage 2 payment (as the Skipton argued my fibroscan reading was below their cut off criteria).

30. I would say that it is probably easier getting blood out of a stone than getting money out of the McFarlane Trust. I was refused a grant for a new mattress

when it was very much needed because of night sweats. They would also argue that you are not entitled to additional discretionary payments if you were in receipt of DLA. That is no longer the case with EIBSS.

**Section 8. Other Issues**

31. There are no other issues.

**Anonymity, disclosure and redaction**

32. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I am prepared to give oral evidence to the Inquiry if required.

**Statement of Truth**

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

Signed. GRO-C

Dated 26 - Nov - 2018

### Medical Summary

(This summary is not intended to exhaustive but sets out key points in the records relevant to the statement)

- 31.01.1977 'No recent HIV antibody (*Hospital record*)
- 1981 First treated with FVIII (*UKHCDO Patient annual treatment record*)
- 15.02.1987 First positive HIV test result (*UKHCDO Patient HIV Data*)
- 1983 – 1987 (*UKHCDO data and medical notes and records missing*)
- 27.02.1987 HIV diagnosed and patient told (*Hospital records*)
- 1992 HIV diagnosed (*Hospital 'Summary for Case Notes' dated 15/3/12*)
- 01.01.1999 HIV diagnosed (*UKHCDO Patient HIV Data 'Condition Information from SD'*)
- 20.11.1992 Diagnosed with HCV.
- 2005 First clearing treatment for HCV.
- 18.02.2009 Confirmation of 'acquiring HIV and HCV before heated treated product introduced.' (*Hospital record*)
- 2013 Second clearing treatment for HCV.
- 16.04.2012 Confirmation 'HIV and HCV picked up years ago.' (*Hospital record*)