

Witness Name: Michael John Leimanis

Statement No.: WITN6363001

Dated: 22 MAY 2022 .

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF MICHAEL JOHN LEIMANIS

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 December 2021.

I, Michael John Leimanis, will say as follows: -

#### Section 1. Introduction

1. My name is Michael John Leimanis, my date of birth is GRO-C 1955. I reside in Hampshire and details of my address is known to the Inquiry. I am now retired, divorced and have two children. My son is nearly 32 years old and my daughter is 29. I have one grandchild who will be 2 years old in April. I currently live by myself.
2. Formally I was employed by HMRC for 25 years as a Tax Investigator. Following this I was head-hunted by Coopers & Lybrand (based in Reading) who later merged with Price Waterhouse where I was promoted to Manager within a year. Initially I was based in Windsor and I was later transferred to the Uxbridge office. As I will explain later, it

was incredibly difficult being ill and managing a demanding job at the same time. I lost my job, my marriage and my home.

3. I was diagnosed with Von Willebrand's disease although now there is a big question mark as to whether that is true. My medical condition currently under investigation at Basingstoke and North Hampshire Hospital to assess whether I have Von Willebrand's. I certainly have some kind of blood disorder. I intend to speak about my infection with Hepatitis C ("HCV") that I received as a result of being given Factor VIII. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment I received and the severe impact it had on my family life and career prospects.

## **Section 2. How Infected**

4. When I was young (around 8 or 9 years old), I found that I tended to bruise easily. An example of this would be when I was learning to ride a bike. I also used to suffer from a lot of nosebleeds (which was another indicator that there wasn't something quite right with my blood). To investigate these issues, they sent for me tests at St. Mary's Hospital in Portsmouth. I was under the care of Dr O'Brien. I wasn't given any formal treatment at that point. In order to mitigate the risks, I would be extra cautious when I was taking part in school sports.
5. In 1968 or 1969, I was diagnosed with Von Willebrand's disease. My GRO-C also had it. GRO-C was diagnosed with Von Willebrand's but to a lesser degree. As my medical notes indicate, that diagnosis has later been questioned by specialist haematologists. Since then, they have diagnosed me with a bleeding diathesis and an atypical form of Von Willebrand's. I carry a Bleeding Disorder Information medical card with me (provided by St. Thomas' Hospital). This identifies my blood condition. The card alerts the medical profession to contact St. Thomas' before starting treatment. Often, medical teams are reluctant to do this.

6. I first had Factor VIII in the aftermath of suffering an injury to my right hand, resulting in a haematoma and swelling, when I was around 23 years old. It bled internally but not externally. Initially, I was seen at St. Mary's and the Royal Portsmouth Hospital (which no longer exists). Dr Shelswell (a Consultant doctor) treated me at the Royal Portsmouth Hospital. After various treatments, like an ice compress, I appear to have been given the first shot of Factor VIII in December 1978 by Dr O'Brien at St. Mary's. On or about 15<sup>th</sup> January 1979 and in February 1979, I was given more injections of Factor VIII by Dr O'Brien. As it didn't improve, it was recommended I travel to Nuffield Orthopaedic at the John Radcliffe Hospital in Oxford. There I was treated with more Factor VIII which still didn't work. As a result, I had an operation to excise the haematoma. During that operation, I may have been given Factor VIII again. In total, over the period of more than a year during my injury, I was given two or three lots of Factor VIII. At no stage was anything mentioned to me about the potential risks of infection from using blood and blood products.
7. There were a few further injuries where I may have been given Factor VIII. In 1993, I had an operation on my face because I had a tethered sinus on the bottom of my jaw that needed to be cut out. I was given Factor VIII and DDVAP, a synthetic medicine designed to boost Factor VIII. The consensus regarding the treatment I was given was that I was not responsive to DDAVP alone and required Factor VIII to reduce bleeding despite my near normal Factor VIII levels.
8. In 1986, I developed a haematuria and Glomerulonephritis (inflammation of the glomeruli in the kidneys). Professor Dusheiko's opinion was that there was a link between Hepatitis C and these conditions. In February 1987, my serum ASTs were raised (93 U/L). Nothing was done about it. There is a possibility that in 1986, I already had Hepatitis C. Professor Dusheiko never physically examined me, but he pulled together my medical records and history in order to extrapolate conclusions about my case.

9. On 20<sup>th</sup> July 1992, I received a letter from St. Thomas' Hospital diagnosing me with Hepatitis C. It was quite blunt. I was not given any real information about the virus and its ramifications. I was referred to the Haemophilia Unit at St. Thomas' after my local unit closed down in Portsmouth. I went there regularly for blood tests. I have been told that the infected blood I was given had been tracked down to a source in Pakistan.

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

10. I do not believe I was infected with any other infections other than HCV as a result of my treatment with blood and blood products.

### **Section 4. Consent**

11. I do not believe I have been tested for anything against my will or without my consent for the purposes of research. The only trial I have been involved in was HCV RUK.

### **Section 5. Impact**

12. I learnt I had been infected with Hepatitis C on 20<sup>th</sup> July 1992. That was a traumatic time. It came as a shock as I was asymptomatic. It's an insidious disease in that it is so slow, I hadn't realised that things were changing. It wasn't fully explained to me what could happen with Hepatitis C.
13. It was only as a result of my work that I realised the terrible impact of Hepatitis C. I had a high-powered and stressful job that I couldn't cope with because of my illness. On joining Cooper's, I disclosed that I had Hepatitis C. Initially there was a question mark over whether they could take me on – luckily, they did. I was promoted to Manager after 12 months. The brain fog severely impacted my work. It was a demanding

role that required me to be performing to a high level— not least because I had a daily commute to Uxbridge leaving home before 5am and returning home around 7.30pm. I used present many meetings and seminars, but this became increasingly more difficult because I couldn't concentrate on anything. I had a lot of anxiety and fatigue. At the time, I put the symptoms I was experiencing down to the stressful job. But, in hindsight, they were side-effects from my infection. When my work started to fail, I started to research symptoms of Hepatitis C and it all made sense. It was difficult to persuade my employer that I had serious health issues because outwardly I looked completely fine. In reality, I was very ill.

14. St. Thomas' Hospital wrote to the HR department and occupational health at my firm asking if they could send me to a local office (instead of London) in order for me to better manage my symptoms of Hepatitis C. They did that, but it didn't work out – it was lower pay and I was doing a different job. Eventually, I was dismissed in August/September 2009 as I was no longer able to function and fulfil my duties. It was a career that had fine prospects but disappeared because of my Hepatitis C infection.

15. After leaving PWC, I was unable to find any other job. Everything fell apart. I was unemployed and bankrupt. Once bankrupt, it means you can't find any job in the financial sector because you are immediately ineligible. It also makes everyday life very difficult: for example, I couldn't even get a debit card. I would not have become bankrupt if I didn't have Hepatitis C.

16. Inevitably, there was also a massive impact on the family. I had to be careful and take extreme caution when bodily fluids were involved, for example, keeping my toothbrushes separately. At the point of finding out I was infected with Hepatitis C, my wife GRO-C and that caused major concerns regarding transmission of the infection.

17. Although my wife and I have a good relationship now (for example, she even recently took me to Basingstoke for a blood test), things went downhill after I started treatment. It led to the break-up of my marriage. She couldn't cope with my treatment and its side-effects. It caused a lot of problems at home as I was off work on sick leave during this time. The debilitating effects included symptoms such as severe flu, nausea, extreme fatigue, drowsiness, anxiety, headaches and irritability. My job went pear-shaped and one thing led to another. It totally destroyed our lives. When the marriage was breaking down, my children were in their early teens. My daughter stayed with her mother, and my son came with me. I moved into rented accommodation which was just a flat above some shops.

18. Even now, the impact still lingers in terms of my family relationships. I don't see my daughter as much as I used to. Birthdays and Christmas are really the only times we're in contact with each other.

19. I have cirrhosis as a result of my Hepatitis C infection – which can potentially shorten my life. It also means that I can't drink alcohol. I maintain a healthy diet and lifestyle to mitigate its effects.

20. I kept my Hepatitis C diagnosis close to me because of the stigma associated with it. My family knew about it and just 2 or 3 close friends. I feared that I would be ostracised if I declared it publicly. People, at the time, didn't differentiate between Hepatitis C and HIV. I only told one of my friends as he was then going through chemotherapy treatment. In effect we supported each other. I remember there was an incident at GRO-D Hospital where the phlebotomist insinuated that I was a drug user who used dirty needles. I was absolutely shocked and disgusted at that. I wish that I had made a formal complaint about her assumption at the time but I was too taken aback by her reaction to respond.

21. If I didn't have Hepatitis C, my life would be very different right now. I would still be married, still have a great career and wouldn't have been made bankrupt. I don't tend to dwell on it, but there is also the loneliness, which has a severe impact on all of this. Back then, we had a spanking new three-bedroom house and things were looking up. I know these are materialistic things but it's painful to know that it was all shot down in flames because of something outside of my control.
22. I feel particularly aggrieved that the Factor VIII treatment (which gave rise to me contracting Hepatitis C) was totally unnecessary. I should not have been given Factor VIII in the first place.

#### **Section 6. Treatment/Care/Support**

23. On 4th January 1996, St Thomas' Hospital advised me to have a liver biopsy. It was said at the time that I was genotype 3A which was said to be usually very responsive to Interferon. Anecdotally, it seems like that is not quite correct. That treatment didn't happen. Subsequent research has shown that genotype 3 has emerged as the most difficult HCV genotype to treat.
24. I undertook and completed a 24-week course of Pegylated Interferon/ Ribavirin in March 2005. Unfortunately, I did not achieve a sustained positive virological response and my Hepatitis C viral load remained unchanged. I was also informed that there was no further treatment available.
25. For that treatment, I was self-injecting and taking daily Ribavirin tablets. That really dragged me down. It was horrendous. Whilst it was fine for the first few weeks, the side-effects started to emerge and it was terrible. Towards the end of the 24-week period, I couldn't even get out of my chair to do ordinary house hold tasks. I was warned about the side-effects and told that they were akin to chemotherapy. That turned out to be true. In hindsight, it exaggerated the symptoms that I wasn't

aware of. Once I became aware, it had a negative effect on my well-being. I used to get quite anxious because I felt as if I wasn't in control anymore in terms of the tiredness and fatigue. It's very hard to describe: I found it difficult to be ill and not know what was causing it. I never received any offers for psychological support.

26. Around 2014 or 2015, they said there could be treatment available but it couldn't be undertaken unless there was sufficient funding for it (which there wasn't at the time).

27. In May 2015, I was recommended to take Pegylated Interferon, Ribavirin and Boceprevir treatment. However, in a letter from St. Thomas' Hospital to King's College Hospital, they said that although I qualify for this treatment, it was likely to be poorly tolerated by me because of my thrombocytopenia. In January 2016, I was invited to take part in the Merck trial using experimental drug Mk-5172A (Elbasvir/ Grazoprevir) alongside Sofosbuvir without Ribavirin. This treatment lasted for 12 weeks – half the time of the original treatment. This round was successful. Hepatitis C was not detected from week 4 of the treatment. They confirmed on 28 April 2017 that I was cured of Hepatitis C.

28. However, they also indicated that I am cirrhotic. I previously had a Fibro Scan at St. Thomas' that indicated this may be the case and this may have been what accelerated my need for treatment. As a result, I would need regular Hepatitis C surveillance. As there was no longer a need to travel to King's College Hospital, I was transferred to be looked after under the care of Dr A Fowell at Queen Alexandra Hospital in Portsmouth. My last Fibro Scan showed that my liver has slightly improved but is still cirrhotic. The risk of cancer hangs over me. I previously had a liver biopsy at St. Thomas' Hospital when I was an inpatient. I recall, it was a very invasive procedure.



## **Section 7. Financial Assistance**

29. I have received the Stage 1 and Stage 2 lump sum payments from the Skipton Fund and am currently receiving financial assistance from the England Infected Blood Support Scheme ("EIBSS"). It was a straightforward process to access these payments. St Thomas' Hospital gave me the forms and they sent it off on my behalf. Without these payments, I would not be able to survive. They are incredibly important. However, what I have found really frustrating was the inconsistency in the payments between Scotland, Wales and England.

30. I am in receipt of a Civil Service Pension which commenced early in February 2014 after attending an interview and being brought forward on the grounds of ill health. From this year I am also in receipt of the state retirement pension.

## **Section 8. Other Issues**

31. Someone needs to be held accountable and take responsibility for the failures that led to this catastrophe. There needs to be proper redress. Nobody has said 'I'm sorry'. Kenneth Clarke's evidence given to the Public Inquiry was shameful – he accepted no responsibility at all for what happened. I hope the Inquiry can hold someone to account for the things that clearly went wrong.

## **Statement of Truth**

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

Signed

GRO-C

Dated

07 MAY 2022

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