

Witness Name: Alison Ryan Purseglove

Statement No: WITN3056001

Exhibits: N/A

Dated: 5 May 2019

## **INFECTED BLOOD INQUIRY**

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### **FIRST WRITTEN STATEMENT OF Alison Ryan Purseglove**

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1. I, Alison Ryan Purseglove, of Lettrell, Stoke Trister, Wincanton, Somerset, will say as follows:

#### **BACKGROUND**

2. I am the widow of Ian Stewart Purseglove. Ian was born in South Dorset on GRO-C1943. At the age of one year, he ruptured a vein in his lip and it would not stop bleeding. His life was saved by the intervention of the US Military medical teams waiting in Weymouth for D Day. He was diagnosed as having haemophilia at that time. Later the diagnosis was refined to being a severe Factor IX deficiency (Haemophilia B or Christmas Disease.)
3. Ian's childhood was characterised as a series of hospital stays to manage bleeds into joints, including one which left him in Lord Mayor Treloar hospital for a year on traction. However, he became an outstanding musician with a career as a performing pianist or organist in his sights. While performing he suffered a catastrophic bleed into his left wrist, which destroyed the nerves. Surgery was carried out to correct the resultant

contracture in 1966 and some ill-judged care left his left hand permanently paralysed, and a performing career was no longer available to Ian. He became a music teacher, composer and examiner and took up the French Horn.

4. We met in 1982 and married in 1985.
5. Ian was a busy person always trying to make something of his life, despite the pain from his damaged joints. By the early 1990s however, he was clearly quite unwell and it transpired that this was HCV infection and in December 1995, end stage liver disease was diagnosed. A transplant was performed in 1996 and after a few months Ian returned to his busy life, at last free from haemophilia – but not from HCV.
6. However, his health became increasingly unpredictable resulting in many hospitalisations for a variety of serious events. He lost the ability to work full time. I gave up my very senior job which required considerable travel and took one which ensured I was home every evening to care for him.
7. By 2006, Ian's life was very constrained. Although only 63 years old, he behaved like someone in their 90s because of general frailty and considerable pain. In his last two years of life, he was very weak and, although determined to survive, still playing the organ in church which he deemed to be his duty, even though he needed a wheelchair to get there. The degree of his debility is indicated from the fact he received the highest level of Disability Living Allowance from 1996 onwards and, while regularly reviewed, this was never withdrawn.
8. Ian endured a horrible death in Yeovil hospital on 8<sup>th</sup> March 2014.

#### **TREATMENT AND ITS IMPACT**

9. Before the surgery on his arm in 1966 in Oxford, Ian remembered Professor Duthie coming to his bedside with two bottles of white fluid announcing that this was the entire UK production of Factor IX for a week and was to be used in the next day's operation.

10. When Factor IX was available more readily it was administered at Dorchester Pathology Lab prophylactically on a weekly basis and to correct any bleeds. Ian could not self-administer because of his LH paralysis. When I became engaged to Ian, I took over administration.
11. We became aware of the risks of HIV infection through the Haemophilia Society. In late 1984/early 1985 I attended a regular Blood Donor session and checked with the doctor in charge whether it was still appropriate for me to give blood, given these concerns. They were unaware of any issues and I donated as usual. A few weeks later I received a letter telling me that I was indeed too high risk to give any further blood.
12. At the time of our marriage we knew about the risk of HIV but Ian had not been tested. When he was tested in 1986, he was negative<sup>1</sup> but he was told at the time there "were some issues with the liver" and Non A Non B Hepatitis was mentioned. He said at that time that he "*felt he was crawling with viruses*". He felt unclean and that he would contaminate anyone he touched. As a result, from that time our marriage was celibate.
13. In 1992 he was diagnosed with Ca bladder, Type 2 diabetes and also Hepatitis C which we understood had been contracted through his Factor IX treatment. We were unclear what the implications were and as far as I remember until 1995 LFTs were not carried out. If they were the results were not shared with us. For instance, he was never told to stop drinking alcohol. However, for a brief time Interferon was tried to see if it would help. It did not.

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<sup>1</sup> The West Dorset Director of Public Health issued a press statement saying that 4 out of the 5 West Dorset haemophiliacs were HIV positive. This made the front page of the Dorset Echo. Ian's haemophilia was well known because his musical accomplishments, remarkable for anyone with his problems, had been widely publicised. Not long after he was told there was no further teaching available for him at a very prestigious high profile school where he had been a very successful instrumental music teacher for some years.

14. End stage liver disease was diagnosed in December 1995 and Ian was put on the urgent list for transplant. A liver was not available for 6 months. During this time the Liver Unit at QE hospital in Birmingham was clearly having to learn about haemophilia. For instance, after a bladder biopsy they failed to catheterise him not realising that he was likely to bleed at any point. By the time this mistake was rectified his bladder contained 1.5 litres of blood and he very nearly died. They also failed to realise that if his gums were bleeding, and this was not controlled, considerable amounts of blood would be ingested and, because his liver could no longer digest protein, hepatic encephalopathy would, and did, result. Again, he nearly died.

15. After the very successful transplant on June 4<sup>th</sup> 1996, a stream of doctors came to check whether the haemophilia really had been cured. They believed Ian's might have been the first transplant of a Factor IX deficient person anywhere in the world. Care for his liver was thereafter shared between QE Birmingham and Yeovil District Hospital.

16. Over the next few years Ian suffered from and was hospitalised for:

- Central Retinal vein occlusion losing the sight in one eye – possibly as a result of immunosuppression
- A severe and dramatic variceal bleed in 2005 requiring urgent surgery (and a fair amount of domestic redecoration)
- A transient episode of liver rejection in 2008.
- Several collapses and admissions to hospital following unaccountable and sometimes bizarre symptoms such as turning bright red and running extremely high temperatures.
- Severe nephritis
- Severe labyrinthitis
- His Type 2 diabetes became insulin dependent

17. At least the bladder cancer was well controlled. As time went on I became rather more Ian's nurse than his wife.

18. In 2004, Ian received news that he had received Factor IX which was high risk for being contaminated with nvCJD. This confirmed the very damaging and negative feelings he had about himself and his

"uncleanness". It was a very depressing time for him. It also greatly complicated treatment and investigations for the various events which happened. Endoscopies, cystoscopies etc were all made more difficult because of the equipment decontamination requirements and were sometimes very delayed, as a result. This was, in particular, the case at the end of his life.

19. Despite all this, Ian survived. He was extremely compliant with his medication. Even when very ill he would ensure that his immunosuppression was taken accurately and on time. He was also remarkably resilient and preferred not to notice when he was actually becoming very ill. My work from 2004 was in palliative and end of life care and in the two years before his death, I could tell that he was dying. This appears to have escaped the notice of the consultants, in both QE Birmingham and Yeovil, who were fixated on spotting when the transplanted liver would succumb to reinfection. This had not happened to a significant extent, at the time of death (although the post mortem did show cirrhosis). However, in the last three months, the decline was very rapid and Ian was admitted to hospital where he died before a diagnosis had been agreed. The hospital was unprepared for the death and as a result it was, to my sadly expert eyes, extremely badly managed, protracted and distressing for both Ian and me.

20. At the following Inquest the Coroner found that Ian "*died from a known complication of a necessary life-saving liver transplant.*" The given causes were;

1a) Perforated jejunal diffuse large B-cell lymphoma with peritonitis

1b) Post liver transplant lymphoproliferative disorder [PTLD]

2i) Upper gastro intestinal haemorrhage with severe ulcerative oesophagitis

2 ii) Hepatic cirrhosis

21. The fact that the liver disease which gave rise to the need for a transplant and the cirrhosis was HCV, or that this HCV was caused – "*a known*"

*complication*" - by the treatment of haemophilia with blood products contaminated with the virus, was not mentioned. It would seem that the inquest did not record the proximate cause of death – namely the giving of contaminated Factor IX which caused the HCV which caused the end stage liver failure which caused the transplant which ultimately caused the PTLD which caused the death.

### **THE EFFECT ON ME**

22. As a spouse of an infected haemophiliac it was recognised that I was at risk of infection – which is why the Blood Donor service were no longer prepared to accept me as a donor.
23. Spouses of haemophiliacs are at risk not just from sexual transmission. Ian regularly bled from his gums and a bleed overnight could leave us (and our bedding) both covered in blood when we woke up the next morning. In addition, in the couple of episodes of extreme bleeding (such as the variceal bleed in 2005) and when he was so ill he was doubly incontinent at home – a regular occurrence – I was exposed to considerable risk.
24. Yet at no time was I offered an HCV test. I requested and was given one in 1996 after the transplant and in 2014 after my husband's death. Both results were negative. However, had I not made that request I might now be carrying the virus in its latent form, and indeed passing it on inadvertently. If spouses/partners of people who are known to be infected are not routinely being reached out to, to ascertain their status and ensure help is given, there may well be considerable numbers who have been affected and infected by contaminated blood who are invisible at present.

### **Statement of Truth:**

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

Dated the 5 day of May 2019

Signed:                     GRO-C