

Witness Name: Alison Bennett

Statement No.: WITN0553/001

Exhibits: **WITN0553/002**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ALISON BENNETT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 September 2018.

I, Alison Bennett, will say as follows: -

Introduction

1. My name is Alison Bennett. My date of birth and address are known to the Inquiry. I am a retired anaesthetist. I intend to speak about my son, Alistair James Bennett who was infected with HIV and Hepatitis C via Factor VIII blood products. He was diagnosed with HIV in 1985 and died of AIDS in 1995. In particular, I will discuss the nature of his illness, how it affected Alistair, myself and our family, the treatment he received and the impact it had on him and our lives together.

How Infected

2. Alistair was born in April 1972 and diagnosed with severe Haemophilia A (Factor VIII <1%) when he was about 8 months old. There was no

family history of Haemophilia and we were told it was due to spontaneous genetic mutation. Although he was symptomatic from a very early age (a matter of weeks) and was referred to paediatricians, there was some delay in diagnosis and he received no treatment until December 1972 – a transfusion of whole blood.

- 2.1 Once the diagnosis was confirmed, he was treated with cryoprecipitate supplied by Royal Manchester Children's Hospital (RMCH) and sourced from the Blood Products Laboratory (BPL) in Elstree. Fortunately, I was able to give Alistair his injections and consequently, we were allowed to begin home treatment in September 1973 when Alistair was aged 17 months. We used cryoprecipitate from RMCH.
- 2.2 Whilst he was young, Alistair would additionally be treated at Truro Haemophilia Centre, on the occasions that we were holidaying in Cornwall.
- 2.3 His registered Haemophilia Centre was RMCH until he went to Newcastle University in 1990 and transferred to the Newcastle Haemophilia Centre aged 18 years.
- 2.4 The centre director at RMCH was Dr D I K Evans. In the last two or three years of his life when he was too unwell to be in Newcastle, Alistair was also treated at the Haemophilia Centre at Royal Liverpool Hospital.
- 2.5 In 1982, when he was aged 10 years or so, he was treated as an in-patient in the Nuffield Orthopaedic Centre/Oxford Haemophilia Centre under the care of Dr Rizza and Professor Duthie for severe synovitis of his knees and ankles treated by prophylactic Factor VIII concentrate.
- 2.6 Throughout his life, Alistair suffered from significant joint and nose bleeds and I regularly helped him with his injections and mopping up

his nose bleeds. I suffered from Hepatitis B in February 1976, which I often thought I might have acquired from his treatment.

- 2.7 I can't remember exactly when we moved onto freeze-dried concentrate but it was probably when he was six or seven years old in about 1978 or 9.
- 2.8 In the early years of using freeze-dried concentrate this was almost exclusively provided by BPL. However, in the early to mid-1980s there was some problem with supply and we were quite often issued with imported product from the USA - I think not heat-treated.
- 2.9 There had been a programme on television showing the horrors of pooled plasma products and the North West Haemophilia group petitioned the health authority to provide only UK produced Factor VIII. However, this did not happen. My husband and I also spoke to our MP (Den Dover) requesting that the UK become self-sufficient as had been promised by David Owen several years earlier. He (Mr Dover) later wrote saying he had asked a question in the House of Commons, but sadly nothing changed.
- 2.10 I believe Alistair was given infected blood products in this period when imported Factor VIII was being prescribed. I can recall attending the quarterly review clinic in November 1984 when he had been unwell for several weeks with a raised temperature, swollen neck glands and lethargy. No firm diagnosis was made but I think this was when he was infected with both HCV and HIV.
- 2.11 I developed NonA-NonB hepatitis several weeks later in January or February 1985 (later confirmed as HCV) and I feel that the two infections were likely to be from the same Factor VIII concentrate. Happily, I made a full recovery from HCV and have no evidence of HIV.

- 2.12 On 28 August 1985 we received a letter from RMCH (Dr Evans), which informed us that Alistair was infected with HTLV-III (now known as HIV). I exhibit this letter as WITN055/002. We received an extract from an NHS pamphlet relating to HTLV-III infection along with the letter. We received no information about HBV or HCV.

Other Infections

3. In 1990, Alistair enrolled as a student at Newcastle University and therefore registered with Newcastle Haemophilia Centre there. It was during a routine screening here that we learned that Alistair had the HCV infection *in addition* to HIV. We were also informed that his immunity was considerably impaired and his CD4 count very low. No mention of this had been made when he was last seen at RMCH only a month or so earlier.

Consent

4. As I have already said in paragraph 2.12, my husband and I were informed that Alistair had HIV by way of letter which we received in August 1985. We had not been advised that blood had been taken for any of the tests and had not given consent to the investigations and storage of samples
- 4.1 I have no knowledge of whether he was tested or treated for the purpose of research at RMCH or at Oxford in 1982.

Impact

5. As he grew older, Alistair became distressed by the knowledge that he had an incurable disease with no treatment available. To his credit he managed to continue to live a full life, succeed in his GCSE and A Level studies and gain a place at Newcastle University.

- 5.1 During his studies at Newcastle, Alistair began to suffer from increasingly frequent episodes of Septicaemia (now described as sepsis), requiring long periods in hospital for intravenous antibiotics and antifungal drugs. He gradually lost weight, became increasingly fatigued and the episodes of acute infection occurred more and more frequently.
- 5.2 In the last year of his degree, Alistair's immunity became very low and he was admitted to hospital in Newcastle. His housemates were taking their finals at the time but Alistair was too ill to sit his. I went to collect him from the hospital and it was obvious that he wouldn't be returning to University. We engaged with The Royal Liverpool University Hospital under the care of Charles Hay. In the last two years of his life Alistair was constantly in and out of hospital.
- 5.3 There was stigma associated with Alistair's HIV status, which impacted on the way he was treated by other health care professionals. For example, whilst Alistair was at high school, he sustained a blow to the head that led to a tense swelling in his scalp. We took him to our local A&E department to ask if they would aspirate this before the skin became necrotic. We were all distressed by the behaviour of the examining doctor when he learned of Alistair's HIV status. Prior to performing the aspiration, he donned a huge plastic apron, extremely heavy and long rubber gloves (not unlike those a vet might use to examine a cow) and asked questions about HIV at full volume audible to everyone in the department.
- 5.4 Years later, whilst studying in Newcastle, Alistair went to Glastonbury Festival. Whilst he was making his plans, I wrote to the doctor who was responsible for any medical attention needed by festival-goers to ask whether in light of Alistair's diagnosis he could be permitted to use the flush toilets. The response that I received was along the lines of "No he cannot. He shouldn't be going".

- 5.5 In our personal lives we lost friends. Our neighbours' two boys were constant companions of both our children but once their parents learned of the diagnosis, they cut off all of us totally.
- 5.6 With regard to impact on family life, my husband was severely upset by the diagnosis and stigma. He refused to tell his mother until only a couple of weeks before Alistair's death. He blamed me for the situation, as I was the haemophilia carrier and he never got over it. I am sure that this contributed to the breakdown of our marriage.
- 5.7 Alistair's illness also had a significant impact on my career. After I had contracted and subsequently recovered from Hepatitis C and Alistair was diagnosed with HIV it was clear that I couldn't continue with a career in clinical medicine; it was simply too much with a sick child. I therefore obtained employment with the DHSS as an adjudicator in pension claims. I was lucky that my manager was supportive and I was allowed to have special leave when I needed to take care of Alistair. I enjoyed my work, however, had Alistair not been ill, I had planned to qualify as a consultant anaesthetist and spend my working life in clinical medicine.

Treatment/Care/Support

6. As I have noted in this statement, by the mid-eighties I was aware from the media that imported blood products carried a high risk to patients. I wanted Alistair to be provided with only UK products. However, when we collected our supplies of Factor VIII, we had no control over where it came from and so Alistair was forced to use products which were made with imported blood products.
- 6.1 At no point was Alistair offered counselling or other forms of psychological support. The doctors and nurses who treated him in Manchester, Liverpool and Newcastle were fantastic and I felt that I had the support that I needed and I think that this was also true for Alistair.

Financial Assistance

7. Alistair received £20,000 from the McFarlane Trust. He happened to have just turned age 16 years when the class action was implemented and so could apply for and received legal aid. Had this not been the case, I think we would have had to decline to join the action, as we were aware that we would need our savings to provide for him in the future. All we were required to contribute was £100.00 as “best friends”.
- 7.1 However, because he was only young when the sum was awarded, he only qualified for a low payment. We felt aggrieved by this. The award was dependent on agreeing to a no-fault compensation package and to give up all opportunity to claim for any other compensation in the future (which proved to be HBV and HCV). We would have preferred to continue with the action but would not have received further legal aid in this circumstance and therefore could not continue.
- 7.2 Alistair died in 1995 and as such, his case was originally not eligible for consideration with regard to the Skipton Fund. However, in 2011 the Newcastle Haemophilia Centre informed us that we might be eligible for an ex-gratia payment. In September 2011, we received £20,000, which was distributed to myself, my ex-husband and my daughter, in accordance with Alistair’s will.

Other Issues

8. It was well recognised from the late 1960s or early 1970s that use of pooled plasma significantly increased the risk of transmission of virus infections, notably HBV. I knew this from my medical training and cannot understand how the NHS sanctioned the purchase of American Factor VIII and denied that there was an increased risk.

- 8.1 Similarly, Kenneth Clarke's denial that there was an association between AIDS and pooled plasma products is incomprehensible.
- 8.2 It is regrettable that David Owen's promise to achieve self-sufficiency in provision of blood products was not carried out by subsequent health ministers.
- 8.3 Since moving to Scotland I have learned that in the 1980s the Blood Transfusion centre at Liberton in Edinburgh had sufficient capacity to provide all Factor VIII and IX requirements for the UK provided blood donations from England and Wales were sent to Scotland for processing. If this had been instituted there would have been no need to import blood products. I hope that the enquiry will determine why this did not happen.

Statement of Truth

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

Signed GRO-C

Dated *22nd November 2018*