Witness Name: Mrs. J V Reid

Statement No: WITN1485001

Exhibits: WITN1485002/3

Dated:11th March 2019

# INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JENNIFER VICKERSTAFF REID					
I, Jen	nifer Vickerstaff Reid w	rill say as follows:-			
<u>Secti</u>	on 1. Introduction				
1.	My name is Jennifer	Vickerstaff Reid. I was born	on GRO-C 1943 and		
	live alone at	GRO-C	, Cornwall, GRO-C		
2.	I make this statement as the mother of Sean David Reid (deceased) who was				
	infected with HIV and Hepatitis C as a result of receiving contaminated blood				
	products and died on	GRO-C 1986. I have anoth	er son Nathan who has		
	contracted Hepatitis C	as a result of receiving co	ntaminated blood products		

3. This statement has been prepared without the benefit of access to my son's full medical records.

and I also had a son who passed away due to a brain haemorrhage.

# Section 2. How Affected

4. My son had Haemophilia A classed as severe. He was diagnosed when he was about a year old as he was crying a lot, so we took him to the doctor who

said that he had an ear infection. We then found a big swelling on his shoulder and went to the local hospital, and this time we were told it was anaemia. He was eventually diagnosed with Haemophilia A

- 5. I was pregnant at the time and asked if my next child could also have Haemophilia. The doctor said "no doctor will give you an abortion". I said I didn't want an abortion, I just wanted to know if the unborn baby was likely to have it as we didn't have a family history of haemophilia.
- 6. Sean was treated with Cryoprecipitate at the Royal Cornwall Hospital (City) Truro. ("RCH") I believe he had his first batch of Factor VIII at the RCH in or about 1977, and he continued to be treated there with Factor VIII until his death. From December 1980 I kept a record of the Batch numbers, dosage and reasons for treatment. I refer to Exhibit WITN1485002. I have also obtained a copy of Sean's records from the National Haemophiliac Centre. I refer to ExhibitWITN1485003
- 7. Sean spent 9 days in hospital testing drugs for arthritis and their effects on haemophiliacs, for research purposes, and I believe this is how he contracted HIV as he was given Factor VIII while he was there which were not the same batch numbers as we had at home. All the batch numbers we had at home were shared with his brother who has only contracted Hepatitis C.
- 8. We were not given any information or advice at all beforehand about there being any possible risk of being exposed to infection.
- 9. In January 1985 Sean was coughing constantly, so the doctor said he would do blood tests, on both the boys. The tests were done three times in total. The first two came back as equivocal. They then had to be sent to Bristol, although I don't know why. I had to ask the doctor if he had received the results after the third test. He said 'yes, Nathan's was ok but Sean is positive'. The tests were carried out between January and March 1985.

- 10. We received no other information than that he was HIV positive. The doctor revealed this diagnosis to me although my son was already an adult and hadn't been asked if I could be told.
- 11. The information we were given was definitely inadequate, we really were told nothing. All the information we obtained was picked up from the TV news and newspapers. We were given no information about how to manage the infection or the risks of others being infected

## Section 3. Other Infections

12. I'm aware my younger son Nathan has received a letter stating he may have been infected with vCJD however as my older son has already passed I don't know whether they would bother to send out a letter if Sean was at risk of vCJD

## Section 4. Consent

13. I do not believe that Sean was treated or tested without our knowledge, or consent, or without being given adequate or full information or for the purposes of research.

## Section 5. Impact of the Infection

- 14. My son had many chest infections and once we had to call the doctor because he was delirious. Sean was in and out of hospital all through this time. We were told me that some of his brain cells had died and he was like an old person, with bad memory, poor balance and always tired.
- 15. He was always coughing, and there were many hospital admissions for chest infections. In the last 6 months of his life he had no social life, he couldn't do anything. He was so slow; he was like an elderly person due to the brain damage from the HIV. Sean suffered headaches, water infections, skin

rashes, thrush, constant colds, bloated stomach, encephalitis, pneumonia, loss of concentration, poor memory, fatigue, blueness of the skin and shortness of breath.

- 16. Before his health deteriorated he was a normal young person who loved parties, discos and going out with girls but for the last six months of his life he was very depressed and withdrew into himself and stayed at home.
- 17. Sean received no treatment at all for the HIV or Hepatitis C. He did receive antibiotics for some of the complications such as the chest infections. I was not aware of what treatments there were available at the time.
- 18. Sean had to go to the Hospital dentist for any dental work but this was down to his haemophilia.
- 19. When Sean went into hospital he was always put into a room on his own and judging by the amount of dust and fluff I saw under the bed, I don't think it was cleaned while he was there.
- 20. It was a horrible time because we couldn't tell people what was going on. If Sean had had cancer people would have rallied round and supported him and us but we felt very isolated because there was no help available. I told my mother and all she said was 'oh he'll be fine'. We also had to protect our other son as he would have been ostracised if the truth came out.
- 21. It has really been just devastating. I have been treated for panic attacks, anxiety, depression, and agoraphobia. After Sean died we went to see him in the morgue and they wouldn't even allow us to touch him. The undertaker came and asked if we wanted to see him again as he had been told that he had to seal the coffin. My younger son was 10 when Sean died so we couldn't explain to him at the time why his brother had passed away in case he blurted it out to someone. I had to go and see the headmaster of his school to tell him that Nathan wasn't infected just in case Sean's HIV status became known.

- 22. The stigma was huge, we couldn't tell anyone. We saw in the papers that people wrote on walls and doors 'AIDS LIVES HERE' and we didn't want that to happen to us. We were under considerable mental strain pretending that all was well for the benefit of our other son and to protect him from abuse and cruel comments.
- 23. When Sean left school he went onto a youth training scheme for a year but then he went back to College to study Art and Biology, but died before he finished the course. His handwriting was always very neat but you could see it becoming almost illegible as he became more unwell. Sean's work also went downhill due to his poor concentration, struggle to get to College, and falling asleep in class. He was reprimanded by his tutors and it was heart breaking because they didn't know the reason and we couldn't tell them.
- 24. My son didn't live long enough for the effects of the Infection to have any real financial effects on him. My husband and I were used to the frequent hospital trips and of course they did cost time and money and he had to take time off work.

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

- 25. We had one major incident; Sean's was struggling for breath and then his lips went blue. We called an ambulance and the ambulance men asked a doctor to assess him. The doctor was very flippant and said 'oh I don't know whether he's breathless because he's anxious or if he's anxious because he's breathless.' When we got to the hospital they were intent on sending him home despite a second episode in the ambulance. When I asked what I was supposed to do if he had another attack he was re-assessed and a member of the medical staff came back and said he was more ill than they originally thought, so he was admitted.
- 26. The haematologist had made an appointment for Sean to have a brain scan, but before we left home he fell down in his bedroom. and I couldn't get him up

so I called an ambulance and we went to the hospital. The doctor asked why I didn't get Sean up and bring him to hospital in the car. I pointed out that Sean was 6ft and it was impossible for me to get him off the floor.

27. We were never offered any counselling and I'm not even sure it was available at that time but it was very difficult to come to terms with Sean's death when there was nobody to talk to about it.

## Section 7. Financial Assistance

- 28. I was made aware of the HIV litigation by the Haemophilia society. I received payments of about £23,500 and £20,000 from the Macfarlane Trust after the 1991 HIV litigation as my son had died. However, to receive this I was made to sign a waiver. I also received £2000 for myself from them.
- 29. The HIV litigation and the payment of any money took a very long time.
- 30.1 received £20,000 from the Skipton Fund in 2011. My claim was originally turned down but after finding information from various doctors to prove that Sean had hepatitis C and pointing out that he had used all the same batches as Nathan, I appealed the decision and it was accepted.
- 31. We had to gather and provide evidence which you would think that they would have access to.
- 32. I don't really have an opinion on the various Trusts or Funds. The only thing I will say is that the compensation for the devastating loss of life as a result of medical negligence was woefully inadequate.

#### Section 8. Other Issues

33. Kenneth Clarke's remarks were absolutely disgraceful and other ministers' actions over the years have been unacceptable. The worst thing for me was that there was no counselling before or after the diagnosis of HIV and Sean's death We were just left to get on with it on our own.

34. In the leaflets from the Hemophilia society they continued to say treatment with Factor VIII was worth the risk which it definitely wasn't and I think this should be looked into by the Inquiry

# Anonymity, disclosure and redaction

35. I do not wish to be anonymous but I do not wish to give oral evidence

#### Statement of Truth

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

Signed	GRO-C		
Datad	11.	03.	2019