Witness Name: R D Kirkpatrick

Statement No: WITN2921001

Exhibits: 0

Dated: February 2019

INFF	CTED	RICOD	INQUIRY

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FIRST WRITTEN STATEMENT OF RITA DOLORES KIRKPATRICK	, k

I, Rita Dolores Kirkpatrick will say as follows:-

## Section 1. Introduction

1.	My name i	s Rita Dolores Kirkpatrick. I was on born	GRO-C	1965 and	
	live at	GRO-C	lamaf	ull time hous	e
	wife with tw	vin boys and am married to Paul Kirkpatricl	k, who has	also provide	C
	a statemer	nt for the Inquiry.			

2. This witness statement has been prepared without the benefit of access to my husband's full medical records.

#### Section 2. How Affected

3. My husband has very severe Haemophilia A and his clotting factor is immeasurable. During the 1980s, at the peak of the Aids scare, he was told by medical professionals that he is the highest blood product user in Northern Ireland. He started taking Factor VIII in May 1976 and he was infected with Hepatitis C sometime after that. He was also infected with Hepatitis B.

- 4. He was treated at the Royal Victoria Hospital in Belfast under the care of Dr Elizabeth Mayne.
- 5. Neither my husband nor his parents were provided with any information regarding the risks of receiving Factor VIII. My husband's parents were told that Factor VIII was a "wonder drug" and that they had nothing to worry about.
- 6. In or around 1983/84, when the AIDS scare was rife; Dr Mayne told my husband that he could be infected with HIV. It was at the Royal Victoria Hospital where he received this frightening information. They took his blood and after a considerable period of time, he was again summonsed to the same hospital where Dr Mayne advised him that he had not contracted HIV.
- 7. In or around 1987/1988, whilst my husband was attending a routine clinic appointment at the same hospital, Dr Mayne very casually slipped into the conversation that he had contracted non-A non-B Hepatitis. Some time after this, he was then told by Dr Mayne, again in a very casual way, that he had Hepatitis C. She told him that it was nothing to worry about as he had probably had it for years and if it had not affected him yet then he would probably be ok. She was very dismissive. Dr Mayne said that they had to give the 'good blood' to the young ones as they were not infected and my husband was to continue to receive the contaminated blood as he was already infected.
- 8. At no stage was my husband provided with any information regarding the management of Hepatitis C or about the risk of transmission to others. Rather, he was led to believe that his infection was a minor issue and that there was no risk of infecting others. My husband always had the greatest faith in his doctors and so finding out everything has been very hard for him; almost as hard as actually being infected. There have been things written in his medical records that are completely inaccurate and this is also very hard for him to stomach. My husband unwittingly put me at risk because he was never advised about the risks of transmission. There was also the sense of feeling foolish and stupid for not working it out for ourselves at this point.

# Section 3. Other Infections

- 9. I cannot remember the date of the letter but I recall my husband receiving one from the Royal Victoria Hospital, advising that he had been put at risk of vCJD. The letter contained a tick box which was to be filled in if he wanted to find out more about this.
- 10.I found it deeply distressing that the hospital told my husband that he had been put at risk of a very serious virus and that they employed the use of tick box to record if patients required further information. I believe that this was handled very badly and this letter had a significantly negative impact on me, in that I became significantly upset. Such was our outrage that we drove to the Royal Victoria Hospital that day to discuss the matter with a consultant (Dr GRO-D), who was able to confirm that my husband had not been given Factor VIII from a vCJD donor.
- 11. Dr GRO-D was shocked that we had driven all the way down just because we were concerned by the letter and merely brushed off my concerns as if they were nothing to be worried about. We knew someone who had died from vCJD and so the illness was of extra concern to us; even though we wanted to believe the doctors' view that it was of no concern.

### Section 4. Consent

- 12. My husband believes that he was probably tested for HIV before 1985 without his knowledge and therefore without his consent. Blood was taken from him on multiple occasions and he was never advised as to why or for what purposes it was required.
- 13. My husband was never advised that he was being tested for non-A non-B Hepatitis or Hepatitis C which it became known as in due course. He was therefore tested, probably numerous times, without his knowledge or consent.

He was unaware that he was Hepatitis B positive throughout this time until he received his medical notes this year.

### Section 5. Impact

- 14. It has been very difficult having all these events as a focal point of our lives once again. I have always tried to block out these memories. It was not an average course of events.
- 15. Throughout the time we were seeking information about Hepatitis C, I was never offered a test, despite my husband insisting on this course of action from the hospital. In the end I decided to see my GP to have a test for Hepatitis C to put my mind at ease. It was embarrassing and difficult to even see the GP in this regard in the mid 1990s when Hepatitis C was talked about in the same manner as HIV. The nurse called out my name in front of everyone and announced that I have having a Hepatitis C test. She then said 'what does a young girl like you need a Hepatitis C test for?' I felt humiliated and mortified.
- 16.My husband told me that if he had not received treatment via blood products then he probably would not be here today. He always felt that he was lucky because he managed to dodge the HIV bullet and he feels guilty that some sufferers were infected with multiple infections following a single treatment.
- 17. My husband suffered a number of side effects following his infection and subsequent treatment with Interferon and Ribavirin in or around 1999. His skin suffered and he developed terrible rashes and he was constantly scratching himself. He had to change all his clothes and bed sheets on a daily basis and he was very conscious that people would notice the state of his skin.
- 18. His skin also turned yellow, he lost weight rapidly, was constantly tired and his personality changed for the worse. I don't know how he did it but he managed to get up and go to work every morning. Looking back, we were both under an incredible amount of stress.

- 19. We had to drive to Belfast every time the hospital wanted bloods and this was a long journey so given my husband's poor health I was disappointed that more effort was not made by the consultants in relation to possibly arranging something closer to home.
- 20.I recall that one of my husband's consultants was called Dr Orla McNulty and when we both advised her that we were trying to start a family she said that there would be no problem in this regard, despite the fact that my husband was still on the treatment of Interferon and Ribavirin.
- 21. It was very difficult for us to conceive so we used IVF. We later found out that people had been removed from the IVF programme if they were undergoing treatment for Hepatitis C. This was very upsetting and it was worrying that mine and our potential unborn children's health had been put at risk.
- 22. My husband and I went through his medical records and found an extract where Dr McNulty stated that she had explained all of the risks of having children while on the Interferon and Ribavirin treatment. I want to record in my statement that this is blatantly untrue because at no point did this happen. I vividly recall our conversation with Dr McNulty and can even tell you which room we were in at the time.
- 23. My husband has never been one to complain but I remember an occasion where a Sister GRO-D was questioning him and his symptoms and this really annoyed him. The nurse was suggesting that my husband was exaggerating and she questioned his ability to cope and deal with things. She totally downplayed his infection and the impact of the treatment for Hepatitis C. Naturally my husband then started questioning his symptoms which was totally unfair.
- 24. Due to all the questioning of my husband's symptoms and the fact that his imagination was running riot I managed to search the drugs company who were providing the Interferon and Ribavirin on the internet by inputting my

husband's patient reference number. I was totally shocked to find out that it recorded how dangerous it was to try for a baby whilst on the treatment and it specifically instructed anyone on the treatment to use two forms of contraception.

- 25. My husband and I went back to see Dr McNulty to show her the results of my research. She thanked us; that was it. I think even then both my husband and I had this innate belief that medical professionals must have known what they were doing and we really wanted to trust them. The fact that this was not the case has had a massive impact on my husband and his lack of confidence in the medical professionals.
- 26. Whilst my husband was still on the treatment, I had a very serious health problem myself which resulted in me having to undergo serious stomach surgery to remove part of my bowel. My consultant was a General Surgeon called Mr Spence who was based in Belfast.
- 27.I explained to Mr Spence about the fact that my husband was very poorly and undergoing treatment for Hepatitis C. He was fantastic and he arranged for me to continue my treatment in Derry to enable me to care for my husband. This demonstrates just how poorly my husband was given that I was discharged to another hospital following major surgery to care for him.
- 28. After we had children, the paranoia of the risk of transmission to our children naturally set in. My husband would not have the children in bed with him and he would not touch their dummies or help with the preparation of their food. It was upsetting because he could not be as close to the children as he wanted. I was in a state of constant worry and trying to balance the fact that we had these two beautiful children but in a backdrop of fear that they would somehow become infected. The stakes changed when we had the children and the anxiety levels were constantly raised.

- 29. To date we have not explained any of this to the children. However, because of the Inquiry and their ages we will now sit them down and discuss matters in full with them.
- 30. We suffered a significant amount of stigma due to my husband's infection. We really struggled to deal with it all and I lost contact with a lot of friends and therefore some friends only know a very small part of who I am.
- 31.A lot of our career choices were made as a result of my husband's Haemophilia and resulting infection. I gave up a huge career opportunity with Shell and a sponsored PhD. I studied geography and geology at Queen's University Belfast and won awards for my academic achievements and consistent results; I received the highest mark of the entire year. This was the first time that a position at Shell had been offered to someone outside of Oxford or Cambridge University so the magnitude of the opportunity was massive. My father and professor thought I was stupid for giving it up and choosing to be with my husband instead. However we wanted children and so the decision was a no brainer for me.
- 32. My husband was still recruited to a fantastic chemical company despite all of his health troubles; however he suffered with the stagnation of a career progression due to his Haemophilia and the resulting infection.

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

- 33. My husband does not have a private dentist and until relatively recently he has always used the hospital dentist at the Royal School of Dentistry in Belfast, situated on the site of the Royal Victoria Hospital; which was a 150 mile round trip journey but he was advised not to approach a private dentist.
- 34. There were periods when the hospital didn't provide a dentist although my husband was never advised as to the reasons why.

- 35. Whenever my husband saw the dentist he was always the last on the list in that he had the last appointment of the day. Any instruments which were used in his treatment had to be thoroughly cleaned and it felt like he was in a bomb disposal unit because the dentists were covered in "bomb disposal suit" overalls which included full face masks. He found the whole procedure very embarrassing and it was very scary seeing the dentists like this and he believes that this had a significant impact on my mental health.
- 36. Furthermore, my husband was referred to the Gastroenterology Clinic due to his bowel problems after the initial course of Interferon/Ribavirin. His bloods were taken and he was initially diagnosed with Coeliac Disease. The normal procedure would then be to progress to a biopsy which would usually be a relatively fast and standard procedure. However, because he had Hepatitis C he was made to go into hospital the day before and spend the entire time in complete isolation. He still suffers from significant bowel related issues.
- 37. My husband also developed a cyst at the base of his throat which was the size of a golf ball. The consultant advised that he could not remove this until Paul had been cleared of Hepatitis C so he suffered a delay in respect of the removal of the cyst.
- 38. My husband also developed sarcoidosis after the interferon/ribavirin treatment. This was a very frightening period as my husband was very unwell and developed breathing issues, he was red flagged to the hospital by his GP for an urgent review and CT scan as there was a fear that it may of have been cancer but it turned out to be sarcoidosis. My husband always felt this was a result of his treatment but the hospital never confirmed it. However there is significant medical research which links the sarcoidosis to interferon treatment.
- 39. Presently we still have clouds hanging over us my husband's brother died four years ago. He too was a severe Haemophiliac who had cleared Hepatitis C but subsequently died of an aggressive cancer which may of have originated

in the liver. As my husband has never had a detailed liver scan we are always fearful that he too get have hidden issues.

- 40. My husband was never offered any type of psychiatric support throughout any of this and I strongly believe that he would have been better equipped to deal with matters if he had been given such support.
- 41.I have never been offered any counselling or psychiatric support.

#### Section 7. Financial Assistance

- 42. In or around the 1990's the hospital advised my husband that he could obtain financial assistance from the Skipton Fund. He received the Stage 1 lump sum payment of £20,000 but he was not entitled to the Stage 2 payment.
- 43. There are differences in the financial assistance offered to sufferers depending upon where they live in the United Kingdom and I believe that this difference should be rectified.
- 44. My husband received a letter in or around 2016/2017 from the Northern Ireland Regional Business Services Organisation, informing him that a new scheme was starting up which would offer support. However he has received no further information or payments from them and it is very difficult to find out information about the new scheme. It would appear that people in Northern Ireland are not being treated the same as people in the rest of the United Kingdom. The Skipton Fund and the subsequent organisation that took over are, in my view, not fit for purpose.

#### Section 8. Other Issues

45.I hope the Inquiry will help provide us with some level of closure and a sense of justice.

- 46. One of the most important things for me is to make sure that something like that never happens again to anyone, in all circumstances, and suffering from any health condition. I hope lessons can be learned from this.
- 47. I feel lucky compared to a lot of affected people and their experiences.

# **Anonymity**

48.I do not want to be anonymous and I do not wish to give oral evidence to the Inquiry. My husband wants to give oral evidence to the Inquiry and I believe that I will need to stay at home and support our children during this time.

#### **Statement of Truth**

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

Signed GRO-C FITH KIRKPATRICK

Dated.....26 /5 / 19