

Witness Name:

Margaret Anne Fitzgerald Statement No.: WITN0050001

Exhibits: Nil

Dated: 18 September 2018

INFECTED BLOOD INQUIRY
FIRST WRITTEN STATEMENT OF MARGARET ANNE FITZGERALD
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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 07 September 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Margaret Anne Fitzgerald, will say as follows: -

## Introduction

- 1. My name is Margaret Anne Fitzgerald. I like to be known as 'Anne'. My date of birth is GRO-C 1953. My address is known to the Inquiry. I have 6 children. I am separated from my husband but we live together in the same house; he wants to stay in the house as he believes it is best for someone to stay with me, due to my illness.
- 1.1. In particular, I will go into detail about the nature of my illness, how the illness affected me, the treatment received and the impact it has had on my life.

# **How Infected**

- 2. In 1985, I received blood transfusions following the birth of my fifth child. I believe this is how I have been infected.
- 2.1. I have never had any tattoos and I have never taken drugs intravenously. I have pierced ears, which I did myself.

#### Infected Blood Inquiry

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## Background

2.2.	In 1985, I went to Gwent Hospital with my husband to give birth to our
	fifth child. My daughter was born in the main delivery room GRO-C
	GRO-C I remember there was total silence. GRO-C
	GRO-C
	GRO-C

- 2.3. The next thing I hear are splash noises. Blood was coming out of me; I was haemorrhaging. The Nurses told my husband to go and I was moved into a theatre from the main delivery room. The Nurses left me in the theatre to go get the theatre staff. When the Nurses came back, they saw more blood. They asked why I did not press the buzzer and I replied that I could not reach it. In the theatre, the Doctors cut off my placenta as it had not detached from my uterus and I was then given blood transfusions: I do not know how many.
- 2.4. There was no conversation about the transfusions and therefore no risks were explained to me.
- 2.5. I was still receiving blood transfusions the day after my daughter was born. My sister remembers seeing me receive a blood transfusion, when she came to see me because that was the day that she had signed the mortgage papers. I do not remember how many pints of blood were given to me.
- 2.6. This was the only occasion was I given a transfusion; I did not have any transfusions with my first 4 children or my sixth and last child. My fifth child is fine and my sixth child GRO-C is also fine.
- 2.7. In the early 2000s, I started feeling very tired, I was sleeping all day and I felt nauseous. I informed my GP and I was going back and forth with tests. My liver count was high and the Doctors thought I was drinking excessively however the truth is that I only drank socially. I did not drink at home and it was certainly not made possible with having six children to look after.
- 2.8. Eventually, in 2005, a locum GP requested for a blood test. About a month later, I got a phone call from the GP and was informed that I have the Hepatitis C infection. I did not know anything about it and thought I would go yellow. My GP could not help either and was upfront about not knowing anything about it. I therefore had no information at that point to help me understand and manage it. Instead I was told that I would be sent to a liver specialist. My family had to research it for me.

2.9. I had to wait 10 months for a biopsy. In 2006, I went back to Gwent hospital 2 weeks later for my results. I was informed that I had cirrhosis and fibrosis. I started treatment around 1 week later and was given information about the infection. I remember that the literature talked about being buried in a lead-lined coffin.

### Other Infections

3. I have not received any other infections as a result of the blood transfusion.

#### Consent

- 4. I did not consent to being treated with the blood products, I was just given it after haemorrhaging.
- 4.1. I am not aware of any other testing that has taken place without my permissions

## **Impact**

#### Mental effects

- The mental effect of being infected with Hepatitis C has been dealing with this everlasting frustration. I kept going back and forth to different Doctors and Hospitals to find out what is wrong with me: they all thought I was an alcoholic.
- 5.1. I was also frustrated that I could not live my life properly. I was tired all the time; I could not run the house and do all the things I wanted to with my 6 children.
- 5.2. I was prescribed anti-depressants but I was not aware of it: as soon as I found out. I took myself off it and it took a couple of months to completely come off it.
- 5.3. My memory has also been affected; I forget and it has gradually become worse. I deal with things as best as possible: my grandmother gave me great advice, 'you have just got to get on with it.' That is how I am living my life.

#### Physical effects

5.4. There are many physical effects, which have grown over the years. In the early 2000s, I was lacking in energy, I was sleeping most of the day and I felt sick. I remember driving to my sister's house and I was suddenly sick all over the car: it was bile. My bones have rotted, I have had to 2 knee replacements and my left knee is not working properly. I

- now have to use a walking stick and for long distances, I use a car provided under the 'Mobility' scheme.
- 5.5. I used to be a chef for a music recording studio that worked with artists such as the band, Oasis. I was working there for 6 years and over the years I just could not carry pick things up. I left because I felt unwell. I did not know that I had Hepatitis C at the time.
- 5.6. I cannot walk properly anymore. If I attend family parties, the restaurant or the pub, I have to plan how to get in, get out and where the toilets are. A relative had her 70<sup>th</sup> birthday party and she had to have it on the ground floor so that I could attend.
- 5.7. I love to travel. However I can no longer go on long haul flights as I have varices. I struggle with short flights. I went away for 1 week but I was very ill. The insurance is also very expensive. I received a quote once for £727.00 for a 1 week holiday: I would rather go to Cornwall.
- 5.8. It takes me longer to do the grocery shopping than before. I used to only take around 30 minutes but now it takes around 2 hours. Sometimes I forget to buys things too.

## Further medical complications

- 5.9. Since my initial biopsy, I have had an MRI scan, a colonoscopy and a gastroscopy on a yearly basis.
- 5.10. As a result of the infection, I have had to have operations on both knees. When I went to have an operation done, I told my Doctor that I had the Hepatitis C infection. The Doctor went to look at the notes and came back and thanked me for telling him as he did not know. There was also another occasion where I had bleeding on my knee and the Nurse went to touch it. I told her not to touch it and to get equipment instead. I had to be proactive as these Doctors and Nurses did not know how to deal with it.
- 5.11. I have been informed that my pancreas does not work properly, which in turn has given me diabetes.
- 5.12. I have also been told that I cannot have a liver transplant due to my other illnesses. I told them I did not want a transplant as I am 64 years old and I want someone who is younger to have it.

### Treatment and effects of treatment for the Hepatitis C infection

- 5.13. I had 3 treatments for the Hepatitis C infection.
- 5.14. My first treatment began around 2005, around 1 week after my biopsy results were given to me at Gwent hospital. I was given Pegylated Interferon and Ribavirin. I took the tablets twice a day and 1 injection

every week at the same time and on the same day. I injected my tummy and was taught by someone at the hospital. I am not sure I much I injected but I had vials. I was on this treatment for 6 months. I had a blood test, which gave me the all-clear. I had a second blood test, which showed that it was not clear. I remember because I received this result whilst I was at my friend's funeral.

- 5.15. The side-effects of the first treatment were: severe sickness every day, which included throwing up water, loss of hair, loss of my eyebrows, infections all the time and poor clotting. If I cut myself, I had to call my daughter. I remember this one time when I cut my leg and blood was coming out of me like diesel; my symptoms were similar to those with haemophilia but I am not a haemophiliac. I was not given a clotting factor but my family had to come to my aid and put gloves on to stop the blooding. I also lost a huge amount of weight. I was 12 stone and I lost 6 stone as a result of this medication. The medical professionals knew about my weight loss and eventually gave me anti-sickness tablets. Despite these awful side-effects, the Doctor would not prescribe a different treatment because it was too expensive.
- 5.16. My second treatment began around 2008. I was given the same medication plus anti-sickness tablets, I was on this treatment for 1 year. I had 2 tablets a day and 1 injection per week. The side-effects were the same. In addition, this time I became so pale that at times, my friend thought I had passed away. I finished this treatment in 2009. Once again, my first blood test showed my liver count was low, which was good. However a second blood test showed that my liver count was high again.
- 5.17. Due to my genotype, the Doctors thought that the initial treatments should have worked but did not. Therefore I was eligible for further treatment.
- 5.18. My third treatment began around 2014. I had this treatment at Gwent Hospital but I was not happy with my Consultant. I requested a change and I was sent to Neville Hall and was under the care of Mr Neville. Mr Neville told me that I will be put forward for a trial drug and that I will be the first to get it. Essentially, I was used a guinea pig and I even had to sign a disclaimer, against any repercussions. I cannot quite remember the names of these drugs and how much I took. I believe one of the drugs started with the letter 'S'. I cannot recall the full name. I was also on Ribavirin at the same time. I believe that the treatment involved an injection and 2 different types of tablets.
- 5.19. The side-effect of this treatment included a blood clot on the left side of my head around the temple region. When I told my Doctor about this, I was taken off the Ribavirin drug and continued with the trial drug. I remember that another man was also put onto a similar treatment plan and he went blind in one eye.

- 5.20. Following the third treatment, I am clear of the Hepatitis C infection.
- 5.21. I have not had difficulties in accessing the above treatments. However, I believe that I should have had other biopsies and treatments much earlier.

#### Medical and/or dental care for other conditions

- 5.22. Due to this infection, my daily life has been taken over by medication. I am on the following medications:
  - Fexofenadine: 180mg, 1 tablet at night, for allergies;
  - Prucalopride: 2mg, 1 tablet twice a day, for bowel problems;
  - Spironolactone: 50mg, 2 tablets in the morning, for fluid/swelling around the stomach;
  - Amitriptyline: 10mg, 2 tablets per night and 25mg, 1 tablet once a day, as a muscle relaxant;
  - Carvedilol: 6.25mg, 1 tablet twice a day, used to slow the heart beat down when it is too fast;
  - Lansoprazole: 30mg, 1 tablet a day, for stomach acid;
  - Inhaler for Chronic Obstructive Pulmonary Disease.
  - *Rifaxmin*: 550mg, 2 tablets a day, for encephalopathy, which is when liquid forms around brain. This began in January 2018.
- 5.23. In relation to Rifaxmin, I was informed by the specialist Doctor that this drug will stop working as it simply eases the symptoms and it is not a cure for my end-stage liver damage. I did not really react to this, I simply resigned to it. As I was not able to take it in, my specialist Doctor told me to look into it further online to help me digest it. I discovered that my life expectancy could only be 6-12 months.
- 5.24. I am just waiting for euthanasia to be legalised and everyone dies in the end.
- 5.25. My Nurse told me that there is another drug, but I have to apply for it in London and they rarely give it because it is too expensive.
- 5.26. I used to be on medication for my type 1 diabetes. I took tablets and was injecting myself 3 times a day. However as my sugar levels are all over the place I have taken myself off it. This was not based on medical advice. Since Christmas 2017, I test my blood sugar levels myself twice a day and only take tablets as and when required.
- 5.27. My infected status has impacted my treatment for other conditions. The encounters with other professionals have left an imprint on my memory.

- 5.28. In 2010 or 2011, after my second treatment, I went to my Dentist as my teeth were rotting. My Dentist explained that this was due to acid coming into my mouth and I was advised to have extraction. My Dentist would not help me after I explained that I had Hepatitis C. He said that he will not do it as she was not clotting properly. He sent me to the hospital but I did not want to get it done there due to the long waiting list. I asked if I could have it done at the Kensington Clinic (a private clinic) and I would be willing to pay for it. He said I have to have it done in a hospital environment.
- I was sent to Gwent Hospital for tooth extraction. I was in the waiting room when I saw 3 people in space suits walk through the waiting room. They were the Dentist and the Dental Nurses. The suits were white, they had a clear cover for the face area and I could hear them breathing. There were around 3-4 other people in the waiting room along with my friend. I was not given any advance notice of this. My name was called and I was told to go into the room where the people in the space suits went. I was told that they were wearing these suits as a matter of precaution. It was bad enough going in there but then to walk out of the room. When it came to leaving, I did not look at anyone and just walked straight out. Everything about this infection was hidden during that period and it was clear that nobody knew how to deal with it.
- 5.30. On another occasion, I went to the hospital as I was unwell. I was turned away as there were no single rooms to treat me. They apologised and sent me home. There was a further occasion where I was unwell and went to the hospital for treatment. This time, there was a single room: the plaster room. I was put onto a trolley as I was highly infectious. It was on this occasion where I was diagnosed with Chronic Obstructive Pulmonary Disease.
- 5.31. After I had one of my knee operations, I had a Doctor who would not examine me. This happened at Neville Hall. Whilst I was in the waiting room, he was blatantly talking about me with another colleague as he kept looking and pointing at me. When I got into the consultant room, he just sat behind a desk and kept asking how I got the infection.
- 5.32. On the other hand, there was another Doctor who personally changed my knee dressing and said that he would do it again. I was impressed by how he dealt with the situation. My Nurse Practitioner, who is a specialist in Hepatitis is also fantastic. Whenever I know there is something wrong with me, I contact her and she helps me to be seen very quickly. She has been wonderful and supportive.

- 5.33. My previous Nurse left the place as she said that she was uncomfortable with the fact that so much hidden over the Hepatitis C infection. She also mentioned to me that if everyone between 1981 and 1991 who had had a blood transfusion were tested for Hepatitis C, it would bankrupt the NHS, which is why they have not done it.
- 5.34. When the Doctors found out about my Hepatitis C, they were prejudiced towards me. I even saw my medical file, which had 3 big stickers on it as a sign that I was infected. There were 2 stickers for blood and 1 for plasma.

## Impact on private, family and social life

- 5.35. After I found out about my infection, I told everyone I knew. Nobody really knew what it was so they had to research it. There were family members who asked if I had AIDS and asked if they can touch me or whether they are able to drink out of the same cup as me. There was an occasion when I was at Church with my friend and she asked if I had AIDS and I had to explain that I did not have AIDS. People can be ignorant and fearful and I always found that I had to explain myself.
- 5.36. The Nurses also looked at me different when I went to have my blood tests taken. There is no way to explain it: they do not treat you like human beings. You also know when the Doctors are lying to you about particular actions that cannot be taken. I just think 'you do not want to do it.'
- 5.37. As time passes, you get used to the stigma. However it should not be this way.
- 5.38. Even after I got the all-clear, there was an incident at my granddaughter's birthday party, where I was bleeding. I was really upset about it. Thankfully, one of my nieces helped to clear up the blood. However another niece then said to my helpful niece that she should get tested.

#### Effects on education

5.39. The infection has not affected my education as I was infected after completing my education. I did not have any plans for further education.

#### Effects on work

5.40. As stated above, I had to stop working as a chef for a music recording studio as I could not pick up things anymore. However I did not know I had the infection at the time. I took up another job as a Receptionist at a beauty salon, where I could sit down. However whilst I was on the job, I found out about my Hepatitis C infection and everything just got a bit much. I just had to quit. I have not worked since then.

### Financial effects

- 5.41. Around 4-5 years ago, social services offered to send someone from an agency to help with the housework and to be with me whilst I shower. I cannot shower by myself and I need to have someone with me. They said that the person can only be with me for 30 minutes, 2 mornings per week whilst I shower. However this is not enough time as it takes time to get to into the shower, to shower and then come out of the shower. I was told the government legislation said that this is the amount it should take for all of that to happen. I refused to have a complete stranger come to be with me whilst I shower. I do not want them to see me shower.
- 5.42. I have asked my niece to help out. She comes twice a week and I pay her £200.00 per month. She does more for me than offered by social services. I can shower in my own time and she helps with my shopping.
- 5.43. I spent around £4000.00 to have my bath taken out and a shower put in. I was unable to put grab rails in due to the partition walls.
- 5.44. I also spent around £1000.00 to have stair lift built in.
- 5.45. I also put aside £20 per month for my funeral expenses.

## Impact on others

- 5.46. I have had to phone family members late at night or first thing in the morning when I have been very ill during treatment. On one particular morning, I soiled myself and I was in tears as it had never happened before. I had to call my family to help. I was mortified by the entire experience.
- 5.47. On another occasion, I was haemorrhaging and I was sick in the bathroom. My husband is deaf so he would not have heard me calling out for him. I kept passing out. I was crawling on my hands and knees and somehow pulled myself onto my dog to get into the bedroom. I called my friend. When she came around to the house, she saw all the blood and called the ambulance. It was so traumatic that I forgot about my panic button.
- 5.48. My fifth daughter has had to leave work early on many occasions to help me.
- 5.49. Whilst I was on treatment I could not drive. This was firstly because I could not get insurance and secondly because my family would not let me drive. So others had to drive me.

## Treatment/Care/Support

- 6. After my diagnosis with hepatitis C in 2005, which I feel should have been identified much sooner. I believe I was given all the treatment that I should have been.
- 6.1. During my treatment for the infection and related medical conditions, I have been offered support by way of counselling, I have always declined this. I have a strong support network in my family and friends. My illness 'is what it is' and I just get on with what needs to be done.
- 6.2. I have previously tried a hepatitis support group, which was recommended but found that it did not work for me, I only went once.

## **Financial Assistance**

- 7. I currently receive the standard state benefits of sick pay and I did get mobility allowance but now I have a mobility car in lieu of this payment.
- 7.1. I have received 2 payments under the Skipton Fund (which is now the Velindre Trust in Wales), the 1<sup>st</sup> in about 2016 for £20,000, then I received a further £50,000 due the amount of liver damage (cirrhosis and fibrosis) that I have.
- 7.2. I was told that I would be getting this money at the end of 2017, but would have to wait until the new financial year to get it. I received the money in May 2018.
- 7.3. I currently receive £4,000 per quarter from the Velindre Trust.
- 7.4. Although these are significant amounts, I am now too ill to enjoy them and do not have the energy. Therefore I have used most of the money to make things easier for my family. It would have been of greater benefit to me much earlier in my illness to pay for various things including taxi's when I was too ill to walk.
- 7.5. There were no pre-conditions imposed, when I received these payments.
- 7.6. I have faced significant difficulties, obtaining funding from the Skipton Fund. I made 3 previous applications to them to obtain funds and each was declined because my medical records were missing.
- 7.7. 1st application In around 2006-7, I applied for the 1st time first time, and my application was declined, as I told them I had no evidence. The specialist didn't fill in form properly and he just said he had hepatitis C, I expected him to attach my medical records but he didn't, apparently there was no proof that I received a blood transfusion.

- 7.8. 2<sup>nd</sup> application After the end of second my treatment in 2010, I reapplied, but again I was declined, as they had no record of Amy being born. Then a G.P. at my surgery, found a single sheet of paper (she apparently found this within the maternity unit at the hospital) which said how many units of blood I had lost and noted a 'manual removal' under general aesthetic. This again was not thought to good enough proof that I had had a transfusion.
- 7.9. 3<sup>rd</sup> application I think this was about 2 years after the 2<sup>nd</sup> application. A different consultant completed the form and this time he put the genotype and more information about my hepatitis C but again I was turned down as there was not enough evidence of my receiving a blood transfusion.
- 7.10. Final application This was made in October 2017 my G.P. surgery had found my notes (they never told me where they had been) and I applied for Skipton funding again. I have seen the records but I do not have a copy, it is a large paper file with various stickers over it.
- 7.11. I want to know, why my medical notes were hidden away, otherwise how have they now managed to find them?
- 7.12. The Skipton Fund disbelieved me without these notes, were they waiting for me to die? This is what I believed every time they kept turning me down.

#### Other Issues

- 8. The 'big thing' to me, is why was this ever allowed to happen?
- 8.1. Where were my medical notes, covering the years relating to the birth of my 5<sup>th</sup> child Amy. I feel that I was the person who had to do all the asking to find these notes.
- 8.2. If the medical authorities had 'got their act together', I would have had a much better quality of life.
- 8.3. If they knew about this infection, why did they put doctors and nurses at risk? This has worried me for a long time. I felt guilty personally. You can't help thinking this. Why did they put their own people at risk?

# **General comment**

I have made this statement with my daughter Amy present, she is fully aware of everything that has happened to me as she was about 20 at the time of her diagnosis. My memory sometimes lets me down, but once I am prompted with dates and the order in which things happened, I can recall them, which is what has happened during this statement.

## **Statement of Truth**

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

Signed	GRO-C
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Dated 18 - 9 - 18