

Witness Name: Gethin Jones

Statement No.: WITN0821001

Exhibits: NOT RELEVANT

Dated: 9/5/2019

GRO-C

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF GETHIN JONES

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 February 2019.

I, Gethin Jones, will say as follows: -

#### Section 1. Introduction

1. My name is Gethin Jones. My date of birth is GRO-C 1985 and my address is known to the Inquiry. Since I left school I have been a full time carer for my mother. I intend to speak about her infection with Hepatitis C (HCV). In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.
2. I am one of three children; I have a twin sister and a younger brother. As a child I was diagnosed with ADHD, as a result of my learning difficulties, I left school early and have been my mother's carer ever since.

3. I am not legally represented. The investigator has explained the anonymity process to me and I have chosen not to be anonymous. My mother has also made a statement to the Inquiry and has not sought anonymity. I make this statement in support of her and I am therefore happy for my story to also be made public.

## **Section 2. How Affected**

4. My mother was infected with Hepatitis C through a blood transfusion she received following my birth on **GRO-C 1985**. She had a difficult pregnancy and had to be admitted to hospital for periods of rest to prevent her from going into early labour. My sister and I were born via emergency caesarean section in the Nevill Hall Hospital, Abergavenny. My mother haemorrhaged during this procedure and as a result needed to have a blood transfusion to replace the blood she lost.
5. As this was an emergency situation, my mother could not give her consent to the procedure. Whilst this procedure was undoubtedly carried out in her best interests, she certainly did not consent to being treated with infected blood.
6. I found out about my mother's illness when I was around 23 years old in 2009. I believe that the only reason she told me was because she was about to start treatment to clear the Hepatitis C (Interferon/Ribavirin) at this time. It was therefore necessary for her to tell me as we lived together. She knew that I would see her taking the treatment and that I may witness her experiencing side effects of the treatment.
7. I remember that all she told me was that she was going to start treatment. I asked about what the treatment was for and it was only then that she explained to me what had happened to her. She explained to me that she had a blood transfusion when my twin and I

were born and as a consequence received infected blood. She also explained about the infected blood scandal and informed me that lots of other people were also given infected blood. This was the first time that I learnt about the infected blood scandal.

8. I did not ask any more questions at that time as I found it very hard to cope with the news that my mother was ill. My mother is a very private person and kept my siblings and I in the dark about her illness. This was the first time she had ever spoken to me about what was wrong with her.
9. Growing up, I always knew there was something wrong with my mother. She frequently had doctor's appointments and complained of being fatigued and being in constant pain.
10. My mother's symptoms got worse when she started her treatment with Interferon/Ribavirin. She immediately became withdrawn; this was very noticeable as she was always a bubbly person growing up despite her health problems.
11. I noticed that when on the treatment she was always tired and as a consequence she became less active. She seemed to sleep a lot. She always complains about pains in her legs. I knew that she was very stressed by the treatment. It seemed to me like it has aged her. I know that it has taken a massive toll on her life.
12. I know that she had to have injections every week and that they lasted for around a year. The treatment affected her mentally and physically. She was tired all of the time and she found it very difficult to deal with. She had hair loss through the treatment and she suffered dramatic weight loss. She was always a bigger person and as soon as she started the treatment she lost lots of weight.

13. Her mental health also suffered due to the treatment. I believe that it changed her thinking process. I felt like she wasn't there; like she was vacant. I began to find it hard to talk to her, as she was so withdrawn.

14. I was never provided with any information about my mother's Hepatitis C or how to manage it. If I had been provided with information I would have taken that into account. I do not really know how to help; it was always my mother's job to manage her illness. I have never been tested for Hepatitis C, I have been tested for A and B but not C. I wish I had been provided with information so that I could have helped her more.

### **Section 3. Other Infections**

15. I do not know if my mother has contracted any other infections from the infected blood.

### **Section 4. Consent**

16. I am not aware if my mother has been treated without her knowledge or consent. I do not know if she was given adequate information. I am also unaware if she has been treated for research purposes.

### **Section 5. Impact**

17. My mother suffers from mental health problems, which I think have worsened due to her treatment for Hepatitis C. She has had a couple of mental health breakdowns. She has spent time in hospital on several occasions because her mental health was so poor. To my knowledge she has been committed to hospital on at least one occasion because she was a danger to herself. This occasion was around 10 years ago when she went in to hospital for around 2-3 months. I know that she

has been in hospital on other occasions due to her mental health issues; I believe that none of these hospital stays were voluntary.

18. My mother also suffers from physical health problems, which I also attribute to her being infected with Hepatitis C and her subsequent treatment. I have always known my mother to be lively and have an active lifestyle. However once she started the treatment, she suddenly deteriorated physically. This has got a lot worse over past few years she doesn't want to go anywhere, she cannot do chores anymore and is unable to care for herself properly. As her carer I have to do a lot for her, I cook all of her meals and clean the house.
19. I am unaware of any difficulties my mother had obtaining treatment or whether other treatments should have been made available to her earlier. I also do not know if her infected status has impacted upon her medical or dental care for any other conditions. As I said above my mother is a very private person and would not share this sort of information with me.
20. Being infected with Hepatitis C has had a major affect on my mother's social life. I believe she hasn't had much of a life due to her illness. Over the past 20 years she has shown little interest in socialising. Only now she is starting to go out a little bit more.
21. We have not discussed my mother's illness as a family; she has only spoken to people on an individual basis. As a family we found it hard to cope with. I feel that she has missed out a lot of family life because of her illness – in my opinion, she really hasn't had a life.
22. I feel that my mother's illness has had a profound impact on me. I have tried to shut myself off from it but there is no escape for me as I am the carer. I never get the opportunity to go on holiday and I get no respite from the local authority. Occasionally I have to get up and help my mum during the night.

23. I do not really talk about my mother's illness to anyone as I find it really hard. I really keep it all to myself; I am a private individual so find it difficult to talk about these things.
24. When my mother was going through treatment, I remember that people in the area thought the change in her physical appearance was due to illegal drug use. They called her a 'Smack Head'. She tried to explain to people in the area about her Hepatitis C and they chose not to believe her. People in the community assumed that this change was due to a deliberate lifestyle choice of taking drugs and not that she had been infected with contaminated blood. No one knew about the infected blood scandal, for them, this was the only logical conclusion to draw.
25. I became my mother's carer officially around 12 years ago but I have been doing it before this, in an unofficial capacity, since I was around 16. I just got on with life this was normal for me; I had no other choice or option but to help my mother.
26. I have never had time to do educational courses because of the requirements of the carer position. I think this is something I have definitely missed out on. My whole life has been focused on caring for my mother.
27. I believe that being infected with Hepatitis C has taken away my mother's ability to work. She wouldn't be able to cope with going to work. She cannot stand busy stressful environments.
28. I have never received counselling and I don't know whether it would benefit me.

29. My mother finds it hard to find the energy to do anything. She finds it hard to get up and go out to see her grandchildren and other family members.

#### **Section 6. Treatment/Care/Support**

30. I do not know if my mother has experienced problems obtaining treatment.

31. I have never had any counselling and neither has my mother. Today the Inquiry investigators have made me aware of the British Red Cross support line and the services that I can contact to support me after giving my statement. I will give some thought as to whether this is appropriate for me.

#### **Section 7. Financial Assistance**

32. I am not aware that my mother received any financial assistance.

#### **Section 8. Other Issues**

33. I am furious that this has happened to my mum it should never have happened to anyone. I want to know why it happened, I want to know who was responsible and what compensation will be offered to affected individuals and families. I would like to see an apology and a guarantee that this will not happen in the future.

#### **Statement of Truth**

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

Signed

GRO-C

Dated 9/5/2019