

Witness Name: Agnes Miriam Howitt

Statement No.: WITN7539001

Exhibits: Nil

Dated: 20 January 2023

## **INFECTED BLOOD INQUIRY**

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### **FIRST WRITTEN STATEMENT OF AGNES MIRIAM HOWITT**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5<sup>th</sup> November 2018.

I, Agnes Miriam Howitt, will say as follows: -

#### **Section 1: Introduction**

1. My Name is Agnes Miriam Howitt. My date of birth is **GRO-C** 1967. My address is known to the Inquiry. I lived with my partner, Simon John Lemm, **GRO-C** 1969, for 26 years up until his death in 2020. I have six children: Melanie Georgia Howitt, **GRO-C** 1985, Sydney Cain Howitt, **GRO-C** 1991, Jacob Joshua Lemm, **GRO-C** 1996, Jordan Khie Lemm, **GRO-C** 1999, Kyle Zander Lemm and Troy Xenna Lemm, **GRO-C** 2001.
2. I do not wish to be anonymous for this statement.

#### **Section 2: How Infected**

3. In the autumn of 1977, when I was about 10 years, old I suffered from a grumbling appendix. One day the pain got so bad I begged my mother to call

for the doctor. My mother called our family doctor, Dr Mulheron, who came to the house. I recall him pressing on my abdomen and asking me questions. At one point he pressed down hard on my abdomen, and I felt a popping sensation and then the severe pain stopped. The doctor had burst my appendix and had my mother call an ambulance right away to take me to hospital. My mother had to go to work, so Dr Mulheron accompanied me in the ambulance.

4. I was taken to Stobhill Hospital in Glasgow, which was not too far away from my home. I remember all the doctors and staff seemed very worried, but I did not understand as the pain had stopped. When we arrived at the hospital I was taken straight in for an operation, and I was given gas to put me to sleep.
5. The next thing I remember is waking up while being wheeled down a corridor. I could hear my grandmother, who was also called Agnes Howitt, arguing with someone to find out information about me. I remember hearing someone tell my grandmother that they had to give me "a small amount of blood to flush the site" but that I would be fine. I did not hear much more as I then began to complain about feeling discomfort before falling back to sleep. I next woke up two days later because I had developed a fever and I had to be kept on a children's ward for a week. I do not recall being given any other blood or blood products
6. I found out about being infected with Hepatitis C in December 1996. I was in Dorchester County Hospital to deliver my third child Jacob. Just before I was due to go to the delivery ward, I was taken aside by a nurse. They asked me to sit down and then proceeded to ask me questions about using drugs and needles. They then advised that they were able to detect things in blood easier nowadays and that I had tested positive for Hepatitis C. They then proceeded to ask me questions about when and how I had got it. They took another blood sample from me when they told me.

7. I was not expecting to be given this kind of news on the day I was giving birth. I believe I went into shock as I was given such big news and then almost right away was taken to a delivery ward to give birth.
8. I was told about the issue but not how to manage it. I was told what I could expect to be experiencing with Hepatitis C and the risks of passing on the infection to other people. I was very worried that I had passed it onto my baby. There was not enough information provided at the time. Due to the way I was told, and because I was in labour, any information I may have been given I struggled to retain. I recall I went to see my GP after being told of my infection to find out more information about Hepatitis C and what that would mean for me and my health.
9. I believe the manner in which I was told about my infection was not appropriate given the circumstances. I felt that the way I was treated by staff at the hospital completely changed because of the news they had just given me.
10. I do not know if I was informed of my infection at the earliest opportunity, but I believe that the doctors should have known as I had blood tests on prior occasions.

### **Section 3: Other Infections**

11. I do not believe that I have been infected with anything other than Hepatitis C.

### **Section 4: Consent**

12. I believe I was tested on without my knowledge or consent. When I was in hospital to give birth, I was told they would run general tests, which I agreed

to. I was never told that they were testing for Hepatitis C specifically before being told of my diagnosis. I believe they knew I had Hepatitis C before I was told.

13. I was not given adequate information when I was tested for Hepatitis C. I was told upon being given my diagnosis that I would need to have further blood tests but I was never informed of anything prior to my diagnosis.

14. I cannot say for certain whether I was tested on for the purposes of research, but I believe it to be possible.

### **Section 5: Impacts**

15. The physical impacts of Hepatitis C mainly occurred when I was still a child, not long after I had the surgery on my burst appendix. I went from being very bright and sharp to having a terrible memory and not being able to think clearly. My education suffered as a result. I recall one time at school I injured my back and suffered compression of the spine because I forgot how to vault properly on the vaulting horse during a P.E. class.

16. The memory issues, confusion and tiredness led to me sometimes feeling like I was going mad. As a child I would sometimes believe I saw ghosts and thought it meant I was going to die. This led to me being labelled as a "wild child" as I was angry at myself for not being able to be the person I wanted and achieve the goals I had pictured for myself when I was younger.

17. I also used to suffer from hot flushes and would feel like I was losing control of my body, almost like I was having anxiety attacks. My hair also started turning grey at an early age. These symptoms continued right up until I was about 20 years old, but some of the side effects were permanent.

18. I have also experienced symptoms later in life with my teeth. Since having Hepatitis C all my teeth have broken and need to be removed and replaced. I have struggled with access to dental treatment due to my diagnosis. I have never been able to afford to see a private dentist, and I have been unable to be registered with an NHS practice. I would instead have to go to the dental hospital for treatment. This presented further issues as it was so far away from where I lived, and as I had young children that I would have to take with me I would miss appointments. At one appointment when I was younger, I recall a dentist offering to "do me a favour" by removing all my teeth as they were in such bad condition.
19. Mentally, the effects of having Hepatitis C have been traumatising. I have suffered with my mental health since I was a child experiencing the physical symptoms and it has never improved. I was isolated from my family as they looked down on me for not being able to work and make something of myself and without a diagnosis, I had no one to turn to for support.
20. I still worry about the effects of Hepatitis C on me in the future. While I had my blood check multiple times, I never had my liver tested. I have recently had Covid and now I have an inhaler for lasting lung problems. I am worried that because I have been in such ill health any future complications from having Hepatitis C could be severe. This worry has a knock-on effect on my mental health.
21. I faced a lot of stigma after I was told I had Hepatitis C. I lived in Weymouth at the time I was diagnosed and soon after being told I felt like everyone in the town knew I was infected. I ended up moving away from Weymouth because I could not stand knowing that everyone was talking about me, nor the way they would treat me just because they knew I had Hepatitis C.
22. My diagnosis has also had an effect on my children. I believe they would have been traumatised by Hepatitis C when they were younger. Growing up they would have witnessed and endured the stigma associated with their parents having Hepatitis C. My partner was also Hepatitis C positive, but his infection

was still active. He had to go through treatment with interferon and suffered from liver cirrhosis. My partner passed away in 2020 from pneumonia. I believe this was another indirect result of Hepatitis C, as we had black mould in our house, but we could not afford to move.

23. I also used to worry about my children's education suffering because I was unable to support them as fully and thought I may have passed on my own issues with concentration.

24. As time goes by, I realise how bad my situation was, I could not drive because I did not trust myself to drive, especially not with my children at risk. Looking back, I think that Hepatitis C caused me and my family a lot of pain over the years.

25. In terms of my own education, I believe this has greatly suffered as a result of Hepatitis C. I solidly believe that I would have been able to have paid attention more and succeeded at school. Prior to being infected, I was doing really well in school and would get good grades. Not too long after the symptoms started, a school report came back saying they had noticed a change in my work and my grades had become very poor. While I remained very studious and wanted to do well, I stopped being able to concentrate in class.

26. My poor concentration was not only an issue for me at school but also after. I wanted to be a nurse but didn't get the opportunity to do this because I became erratic and wayward. I could not see myself able to work a standard 9-5 job because I had become so erratic and made poor choices. I believe that I would have been an amazing nurse as I have a very caring nature, but there was no opportunity for me to pursue this when I could not even do well in secondary education.

27. I have a deep ache in me that I have never been able to pursue a career, and that I was entering the job scene so late in life, in my 40's, when my children were older. I began working as a cleaner, but I always felt I could have been so much more than this. I also struggled to work as a cleaner even because I could not drive.

28. I have always been furiously independent but it was very depressing not being able to achieve anything at any greater level and this of course had an impact financially. While I claimed benefits, I always qualified for the lowest rate. The only reason I could raise my younger children with any quality of life was down to receiving child benefits. I had to buy clothes from charity shops for first my first child. I was never included in family as I was too poor as they were self-made, and I felt excluded because I could not become more successful. I also faced stigma from my extended family for being poor and on benefits.

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

29. I did not receive any treatments for Hepatitis C. As I was not diagnosed while it was active, I was told that treatment was not necessary because I had cleared the virus spontaneously. I recall that at one point after I was diagnosed, The Royal College in London wanted to pay to take part in medical research looking into spontaneous clearing of Hepatitis C, but I lived too far away to take part. I do not know for sure when I cleared the virus or how long I had it as it did not make me feel constantly very ill, but some of the symptoms I experienced stopped when I was around 20 years old.

#### **Section 7: Financial Assistance**

30. I did not receive any financial assistance from any of the Funds or Trusts. Until recently I was not aware that there was any means of financial support. I was not told by anyone when I was diagnosed or after that these funds existed. In my life I received no support from anyone, and it never occurred to me that there would be.

## **Section 8: Other Issues**

31. I have no other issues I wish to make the Inquiry aware of.



## Statement Of Truth

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

**GRO-C**

Signed A Howitt (Jan 20, 2023 15:08 GMT)

Dated Jan 20, 2023