Name: Gillian Togun

Witness

Statement No.: WITN4921001

Exhibits:

Nil

Dated: 04 - 07 - 2021

### **INFECTED BLOOD INQUIRY**

### WRITTEN STATEMENT OF GILLIAN BERYL TOGUN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 March 2021.

I, Gillian Beryl Togun, will say as follows: -

### Section 1. Introduction

- 1. My name is Gillian Beryl Togun. My date of birth is GRO-C 1968 and my address is known to the Inquiry. I am a teaching assistant at a primary school where I have worked for the last 16 years. I am married with one son and one daughter.
- 2. I intend to speak about my infection with Hepatitis C (Hep C) which I believe I contracted from a blood transfusion following a major operation in 1976. In particular, I intend to discuss the nature of my illness, the treatment received and the impact it had on me.

- 3. I am being supported today by my father as I was very young at the time of the operation and therefore some of my recollections are only approximate. He has helped me to fill in some of the gaps in my memory.
- 4. I can confirm that I am not legally represented and that the Inquiry Investigator has explained the anonymity process to me. I do not wish to remain anonymous.
- 5. The Inquiry Investigator has explained the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

# Section 2. How Infected

- 6. On 11 September 1976, I had been out with my brother to the cinema. He is two years older than I. I can't quite remember the details, but I have been told that as we were returning, we were crossing Cranbrook Road which is very busy. My brother was trying to tell me to cross after a car had passed. However, I simply heard the word cross and so I crossed. The next thing I can remember, I was in an ambulance with my dad. I was taken to King George Hospital in Ilford, Essex This has since been demolished and replaced with a Hospital under the same name.
- 7. My father tells me that on the morning of the accident, he ran about 1 ½ miles to get the ambulance. My mother was playing the organ at a wedding and so wasn't aware of what was going on. She was very distressed when she discovered what had happened.
- 8. Following this, I can only remember snippets. I

recall being in the X-ray department and being asked to move but being in a lot of pain. I did not sustain any broken bones. However, it has been relayed to me that my intestines split open for which I underwent a major operation. I also developed sepsis. My father says that the smell of the infection from the drains I had inserted was immediately discernible as soon as he entered the ward. I remained in Hospital for around 4 weeks during which time I experienced significant discomfort and pain. I was seriously unwell. My father tells me that it was very much touch and go and they feared for my life. He worked as a nurse tutor in the Hospital and at one point was called to my bedside at 2am as my condition had deteriorated significantly. I also became quite delirious during this time.

- 9. I cannot recall any blood loss or blood transfusions however, I have been told that I lost a significant amount of blood. My father does not specifically recall any transfusions or being asked for his consent, nor any warnings about any associated risk being given to him but then he was so worried about my wellbeing that he wouldn't necessarily have registered any of this at the time. I do remember that I had a drain in my abdomen, drips in my wrists and a nasogastric tube.
- 10. Since then, I have not had any major operations which would have required a transfusion nor have I received medical treatment abroad. I have never been an intravenous drug user. I am happily married and do not have any tattoos or piercings. Therefore, I cannot conceive of any source of my infection with Hepatitis C other than the operation that I underwent in 1976.
- 11. Shortly after I started working as a teaching

assistant in a primary school in 2005, I donated blood for the first time in a mobile unit at the Royal Hotel in the town. Within two weeks or so, I received a letter from the National Blood Transfusion Service (NBTS) to inform me that I had tested positive for Hep C. I no longer have this letter. I was provided with a number to contact. I was distraught on receipt of this news. I was aware that Hep C was an illness associated with drug addicts. I couldn't fathom how I could have contracted such a virus. What impact would it have on my career? Would I still be able to work in schools?

- 12. I rang the number provided and spoke to a lady who enquired about the possible source of infection including drug use, operations and tattoos. She advised me to speak to my GP. I also think she might have mentioned Skipton.
- 13. I saw my GP, Dr GRO-D's, at Church Lane Medical Centre in Scunthorpe. She is now retired. I wasn't provided with any information by my GP or the NBTS about the nature of the illness or the potential impact for the future or any precautions to take including of a sexual nature.
- 14. My GP referred me to Scunthorpe General Hospital. The consultant confirmed the presence of the infection. I cannot recall names but I remember him being very blasé. When I expressed my disbelief at how I could have contracted Hep C, he simply responded, 'why?' I was also surprised because I felt very well at the time. I know that the fact I remember this interaction very clearly indicates that it was a negative experience. He referred me to the gastroenterology unit at the Princess Diana Hospital in Grimsby.
- 15. I was seen at the Princess Diana Hospital

around 3 to 4 months later. I was advised on how to take care of myself including which precautions to take and to abstain from alcohol. This wasn't a problem for me. This appointment was more informative than the previous appointment at Scunthorpe General. I saw the consultant every 6 months for a couple of years before being referred to a Hep C nurse specialist. The nurse who I was originally seeing left and was replaced by another, Allison Cartilage.

- 16. I was still travelling to Grimsby initially. However, the nurse had appointments in Scunthorpe every so often so I started being seen there. Allison referred me for a liver biopsy. This procedure was uncomfortable. I experienced migraines afterwards. The result confirmed that I had 'a fatty liver'. I remember this description being repeated quite a few times during the consultation. I can't remember if there was mention of scarring.
- 17. Bloods were taken each time I saw Allison every 6 months. The first time she mentioned treatment was in 2010. At the first appointment in 2005, there was no mention of treatment of any type and there was never any explanation of why no treatment was offered.
- 18. My husband has never been tested for Hep C nor have my children. This was recommended by Allison <u>GRO-A</u>. My children were section births which, we were told, was safer regarding the risk of Hepatitis transmission.

# Section 3. Other Infections

19. To my knowledge, I have not contracted any infections other than Hepatitis C as a result of <u>contaminated blood</u>.

#### Section 4. Consent

- 20. At the time I donated, although I knew that I was being tested for some things, I do not recall being asked to be tested specifically for Hep C. I can picture that I was provided with a form but I am not certain.
- 21. As far as I am aware I have not been tested for HIV.
- 22. I have never been under the impression that I was being treated or tested for the purposes of research.

#### Section 5. Impact

- 23. It is very difficult to identify the physical or emotional impact of an illness that for many years I wasn't aware I had. I have experienced a certain degree of hair loss but nothing excessive. Other than a level of fatigue over the years, I have always been able to function. I didn't notice any other symptoms from the Hepatitis C.
- 24. I started treatment with Interferon in 2010 which made me feel very ill. I self-administered injections into my stomach. I took this in conjunction with ribavirin. I didn't finish the course because blood tests revealed that I wasn't responding. I think I was on the treatment for 3-4 months. I didn't miss any work but I felt very ill whilst there. I had two young children at the time. I struggled with childcare and housework, particularly in the evenings. I was extremely tired, unnaturally so. I also experienced headaches, flu-like symptoms and nausea for which I was given anti-nausea tablets. Allison was monitoring me during this time.

- 25. I was very disappointed that I was unable to clear the infection. I had waited 5 years for medication and you wonder what is next and what damage is being done to the rest of your body.
- 26. Allison continued to reassure me that there were treatments in the offering but that the Hospital were awaiting further information. In around 2013, I began a second course of treatment. I was prescribed Interferon again, this time with two tablets. I cannot recall what they were. After maybe six weeks, this treatment was stopped prematurely as I was not responding. I cannot recall how long it was meant to last. The symptoms were much the same as the first time; headaches, nausea, chills and shaking.
- 27. Again, I was disappointed that I didn't respond to treatment and in fact it was quite crushing. I felt very uncertain about what would happen next. Is this it? Is there going to be any more? Allison sought to reassure me that there was research being undertaken about other treatments. Whilst I believed her, it was difficult not to worry as I wasn't involved in this research and so didn't know what was going on. It did cross my mind that this might be it and I might simply have to deal with the consequences of having Hepatitis C. I tried not to dwell on this. I am of the belief that these things have happened now and one has to move forward and deal with it.
- 28. Between 2013 to 2015, Allison continued to monitor me. In 2015, I began a third course of treatment with Simeprevir. I was provided with three tablets on a daily basis. I suffered with headaches but no other side effects. I believe that I took these for 5 months. I was regularly

monitored. I think I was seen monthly. I got the all clear in 2016. It was a great relief and I felt very happy.

- 29. As I continued to work during treatment, my career progression has not been affected. Nor did I experience financial loss. My insurance has not been affected.
- 30. My diagnosis and resultant treatment did not have any impact on my relationship with my husband. There was no ill feeling.
- 31. Psychologically I was affected by the association between Hepatitis C and drug addiction. I felt dirty. I felt that if I were to share my diagnosis with others, this association would cross their minds too. There is definitely a stigma attached to the virus. As a result, I have not shared my experience with friends and therefore my friendships have not suffered.
- 32. My children are not aware that I was infected. I feel very close with them but at the beginning, they did not inquire about treatments I was undergoing and I left it at that.
- 33. At the time of my diagnosis, my parents were quite concerned. My father was a nurse and understood a little bit about the virus but not a lot. He was aware that it was blood borne and transmissible by infected blood. They also understood that treatments were not available and that the virus could potentially have devastating consequences including the possibility of death. They were worried about my prognosis and what it would mean for me and my family. It was a big relief for them when I told them I had been cleared.

# Section 6. Treatment/Care/Support

- 34. I have never held the belief that the Hospital omitted to provide me with treatments which were available. Nevertheless, in hindsight, I regret not being more inquisitive and assertive about the availability of treatments. I feel that whilst I listening, I could have been more forthcoming in asking questions and finding out more.
- 35. I do not recall ever being offered psychological support or counselling after I was diagnosed with Hep C nor during or after any of my treatments to clear the infection.
- 36. As far as I aware, no other medical procedures I have undergone were impacted by my diagnosis. I had a lovely dentist who continued to provide me with dental services with no problems.

# Section 7. Financial Assistance

- 37. I applied to Skipton in December 2006. I knew from the application form that there was so much information that I was unable to provide and nor could the doctors, as the original King George Hospital has been demolished and rebuilt since my treatment in 1976. King George Hospital, together with Barking Hospital, falls under the Redbridge Health Authority. I haven't tried to contact either Hospital for my medical notes. Furthermore, I moved from llford in August 1981. My GP in llford informed me that my GP notes have gone missing and that they have nothing on record. The doctors at this practise were very elderly in 1981 and I am not confident in how up-to-date their record keeping is.
- 38. On 5 April 2007, Skipton responded requesting further information. I didn't know how to provide this and so I did not proceed

with my application. They wanted proof of my blood transfusion and I thought that was something I could not provide, knowing that the hospital I attended had been demolished and replaced.

- 39. I know that there is only that one route as to how I became infected. There is no other possible explanation but at the same time I realise that I cannot prove it beyond doubt and to me this is what the Skipton Fund required before making any award.
- 40. I have nothing further to add other than I retain my faith in the NHS although I feel that now I am more likely to ask questions and clarify the position – something I may not have done in the past

### Statement of Truth

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

Signed	GRO-C	
Dated 04-07-2021		