Witness Name: Gary William Smith

Statement No.: WITN0714001

Exhibits: WITN0714002-6

Dated: 30<sup>th</sup> January 2019.

### **INFECTED BLOOD INQUIRY**

# WRITTEN STATEMENT OF GARY WILLIAM SMITH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 November 2018.

I, Gary William Smith, will say as follows: -

### Section 1. Introduction

- 1. My name is Gary William Smith. My date of birth and address are known to the Inquiry. I am a qualified counsellor and now work as an emerging trend drug specialist. I intend to speak about my late mother, June Elizabeth Smith (DOB: GRO-C 1937), who had been infected with Hepatitis C ("HCV"), as a result of being given infected blood through a blood transfusion. In particular, I intend to discuss the nature of her illness, how the illness affected her and the impact it had on her and our lives together.
- 2. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

### Section 2. How Affected

- 3. My parents were married for 52 years and have two children, my younger brother and myself. Our family has always been very close Our Mother was a loving and caring Parent and devoted to her family. Home was a very social place and our Mother and Father welcomed our friends and always took genuine interest
- 4. From the age of 30, my mother was diagnosed with Rheumatoid Arthritis and attended a specialist unit at Queen Elizabeth Hospital, in Birmingham and was seen by specialists at the Hospital. Dr Gabatas, my Mothers GP based at the Cronehills Health Centre in West Bromwich. Supported with a series of treatments to help manage her arthritis; this included a period when she was given a series of gold injections. She was also given steroid medication over a long period of time.
- 5. In 1987, my mother's left knee began to bow outwards and was affecting her ability to walk. She met with a consultant at Selly Oak Hospital ("Selly Oak") where they made the decision to offer my mum knee replacement surgery.
- My mother was admitted into Selly Oak for her knee replacement surgery in June 1987; the exact date was around her 50<sup>th</sup> birthday, which was on GRO-C 1987. The day before the operation, my mother's two friends, Doris Hanley and Rose, visited her and whilst they were there, the consultant asked my mother if she had any questions. The consultant explained that with the type of operation she was having it was likely that she will need to have a blood transfusion. My mother touched his arm and asked him if he could ensure that she would not get AIDS. The consultant smiled and said this would not happen.

- 7. The knee replacement surgery was immediately successful; my mother was out of her bed within hours of the surgery and was home two days later.
- 8. In 1993 my mum was taken ill at home and had suffered flu like symptoms. My Mothers GP attended a number of home visits but there was no improvement so the doctor decided to admit her into hospital. Her health deteriorated further, so she was finally taken to a high dependency Unit.
- 9. Due to the severity of my Mothers condition my Father phoned me and asked I come home. When I arrived at the ward, The Consultants were unaware what was wrong with my mother. The consultants eventually discovered that her kidneys were not working properly so they started dialysis. My Mothers condition improved and was then advised that she would have to attend Renal Dialysis Unit three times a week at the Queen Elizabeth Hospital Birmingham. The hospital wanted to set up the dialysis to take place at home, but my Father did not feel comfortable doing this so the dialysis remained in the renal setting. It was later decided to move my mother to the Tipton Dialysis Centre so it was closer to where my parents lived.
- 10. From the commencement of dialysis my Mother became unwell often suffering periods of sickness following dialysis and had a number of hospital admissions due to suffering with underlying infections. My Mothers immune system seemed to be weakened and she was prone to infection. My Mothers mobility became affected and a lift was fitted at home due to my Mother being unable to manage the stairs and eventually lost her mobility completely and became a wheelchair user
- 11. Between the years 1995 1997, when my mother had finished her dialysis at the Tipton Renal unit, one of the nurses took the tubes off the dialysis machine and placed them into a yellow contamination bag. My mother asked the nurse why she did this with her tubes but

not the other dialysis patients? The nurse replied and said: "Don't you know, June?" My mother replied and said "no". The nurse then said: "You've got Hepatitis C" and was shocked that my mother was not aware of this. My mother informed me of this news over the phone, as I was no longer living at the family house.

- 12. My mother then met with the three consultants who had been managing her health. They apologised and said the reason she was not informed of her HCV diagnosis earlier was because they were under the impression that one of the other consultants had already told her. I made some notes re this, which I produce a copy of as Exhibit WITN0714002. My mum told them she did not care about herself; she was just concerned that my brother, father and I might be at risk.
- 13. I have been asked if adequate information was provided to understand and manage the HCV. My family and I were not provided with any information about HCV, nor were we told about the risk of others being infected as a result of the HCV infection.

#### Section 3. Other Infections

14. As far as I know, my mother was only infected with HCV.

#### Section 4. Consent

As far as I know, my mother was always treated with her knowledge and consent. Before my mother had her knee replacement surgery, she was asked about receiving a blood transfusion and she would have given her consent for this.

## Section 5. Impact

- 16. From the commencement of dialysis my Mother became unwell often suffering periods of sickness following dialysis and had a number of hospital admissions due to suffering with underlying infections. My Mothers immune system seemed to be weakened and she was prone to infection. My Mothers mobility became affected and a lift was fitted at home due to my Mother being unable to manage the stairs and eventually lost her mobility completely and became a wheelchair user
- 17. She suffered with Irritable Bowel Syndrome ("IBS") symptoms. She was also eventually diagnosed with having a heart problem and this meant she could not be considered for a kidney transplant. She was constantly in and out of hospital from commencement of dialysis. My Father and I took my Mother out for a drive on her Birthday GRO-C 1998 and on this day she suffered a minor stroke
- I remember the Wednesday evening on 27 January 1999 my mum was in hospital once again. I called my dad and he said I did not need to rush back home and I should wait until the weekend to come home, but when I spoke to my brother, he said I should come back straight away due to his concern about my Mothers failing health. I immediately called the high dependency ward where my mother was receiving care and they asked: "Who are you?" I replied and said: "I am June Smith's eldest son". The nurse asked where I lived and I told her I lived in GRO-C . She said I should make my way home as my Mother was very unwell.
- 19. I arrived at the Unit at 10pm that evening and could hear my mum struggling to breath she was wearing a mask and being given oxygen to assist her, On seeing me my Mother cupped my face in her two hands and told me she was happy to see me.

- 20. On Thursday the 28<sup>th</sup> January my Father and I met with my Mothers Consultants, the consultants were administering a drip to medicate pneumonia due to my Mothers difficulty breathing. I asked them what would happen if the medication didn't work? They said if it did not work, my mother would only have 4-5 days left to live.
- 21. By Friday morning 29 January, my Mothers condition had deteriorated and was only given a few hours to live. I remember the consultant coming to my Mother he asked her "How she was?" and asked her "Have you had enough June?" and my Mother said "yes, she had had enough". During the conversation she was struggling to breathe. He had pulled the curtain around the area while speaking to my Mother. There was a sight gap and my Father and I witnessed the conversation.
- Due to my Mothers continuing discomfort I remember the nurse giving my Mother an injection. My Mother died within a very short time of receiving the injection.
- 23. My father and I remained with her following her receiving the injection attempting to make her comfortable by mopping my mother's brow and we were holding her offering her drinks due to her endless thirst. I remember I felt the wave of life leave her body. My Brother stood at the foot of her bed he saw her eyes rolls back as she took her last breath and died.
- 24. Family members started to arrive everyone was in shock because she had been unwell for so long; we all thought she would make it through. But when I look back with all the knowledge I have now, I realise my Mother had been suffering and had signs of HCV infection. She lacked energy and was more lethargic than normal; she would fall asleep often within the final year of her life. Her face was swollen and it looked very similar to others who had HCV infection. My mother

also had pallor of the skin and her stomach was extended and swollen.

- 25. My Mothers existing condition of Arthritis, Heart Condition, bowel and stomach problems would have been worsened by HCV
- 26. She also had some chronic issues with her bowels. There was incident at home when arrived home from dialysis and needed to use the bathroom urgently. My father attempted to help her access the lift but before she could get there, she lost control of her bowels and there was faeces within the lift area. My brother told me the next morning he heard my Mother crying in the bathroom saying to our Father "she had lost her dignity" My Mother had always been a dignified independent and private person
- 27. An indicator of HCV was my mother's swollen stomach. From the time of knee replacement surgery in 1987, my mother's stomach had become more swollen over the years following surgery this I know is indicative of a liver issue. My Mother was never tested or advised to test for damage to her liver.
- Although my mother was never formally diagnosed with HCV and the health trust have never acknowledged my mother's HCV, I know there is no other way my mother could have been infected with the virus. She did not have any other surgery and nothing in her lifestyle to suggest she could have got HCV; she has no history of drug abuse, no tattoos, no alcohol abuse, no piercings and she was faithfully married to my dad for 52 years.
- 29. Her death certificate does not acknowledge the HCV being the cause of her death. I produce a copy as **Exhibit WITN0714003**, My Mother could only have become infected with HCV through the blood transfusion in GRO-C 1987 and contributed to my mother's untimely passing at the age of 61

- 30. When the family became aware of the HCV, we did not know anything about HCV at the time. Nobody came to speak to us or help and support to identify potential risks within the home, especially in relation to my Father who was my Mothers carer. There was no further contact with our family in relation to HCV again. At the time we had no idea about HCV and the impact on our Mother and risk of infection to us as a family
- 31. All of our relatives and mum's close friends knew about the HCV; we did not keep anything hidden because we were concerned for our Mother who was very unwell prior to HCV. We never felt the stigma of HCV because we did not know what it was and our lives did not change as a result of knowing about the HCV.
- The effects of my mother's illness and declining health did impact me mentally. I have gone through periods of depression since my mother's death and I have recently had some periods of counselling where I have been told that I have unresolved issues in regard to my Mothers illness and death. It is like a black hole; everything always comes back to unresolved issues in regard to my mother's death.
- 33. My brother took our mother's illness very hard GRO-C
  GRO-C
  Our Grandmother Elizabeth
  Whitehouse died aged 89 and our Fathers Mother Alice Smith died
  aged 93, Our Mother died very prematurely aged 61. My Brother and I
  were both quite young I believe the loss of our Mother has had a
  massive impact on our lives
- 34. My father was my mother's main carer for the six years before she passed away and on the surface he seemed to cope My Father died in 2010 and I believe he put on a brave face for me and my Brother. My Father referred to my Mother as his "soul mate" and I believe he never came to terms with the loss of his wife of 52 years. He did

witness how ill my Mother was and had to live with it on a daily basis. I do think when she passed; there was a sense of relief because he knew she was not suffering anymore

- 35. I do not think my mother's HCV had an impact on her medical care or dental care except how she was treated differently at the Dialysis Unit. No Medical professional offered my Mother or our family any advice of support in regard to HCV
- 36. My mother was not offered any treatment to cure the HCV and her liver was never checked or tested by her GP. In my view this was a failing in their duty of care towards her.
- 37. My mum was no longer working when she had the knee replacement surgery so there was no impact on her work. The financial effect cannot be valued because my mother's other health issues masked the physical effects of HCV at the time.

## Section 6. Treatment/Care/Support

- 38. My family and I were never offered any counselling or psychological support when we found out about the HCV
- 39. It is only in the later years that I have received psychological support when in counselling issues of my mother's death have become apparent

### Section 7. Financial Assistance

40. I have previously submitted an application to the Skipton Fund for some financial compensation in August 2017; I have hit a brick wall in regard to accessing my mother's medical records to show evidence of the HCV.

- I contacted the University Hospital Birmingham NHS Family Trust on 23 August 2017 to ask for the records and did not hear anything from them. I sent another letter on 23 October 2017 asking for an update and did not receive a response until 8 November 2017 I produce a copy of as Exhibit WITN0714004, which was vague and did not confirm whether the records had been destroyed. I sent them another letter on 29 January 2018, which I produce a copy of as Exhibit WITN0714005 asking for the Trust to confirm in writing whether there are no records. The whole experience is like hitting a brick wall; there seems to be a real resistance to offer any information at all
- 42. I have also contacted my mother's GP surgery. They informed me because my mother died 19 years ago, they are unable to locate the files, again there appears to be a real resistance in providing me the relevant medical information.

### Section 8. Other Issues

- 43. I have not been apart of any litigation claims or campaigning.
- Financial gain is not the issue here; though it is something my Brother and I are entitled to, any form of compensation is not going to bring my mother back. I want to give my Mother a voice, I want it acknowledged that what happened to my Mother was wrong and should never have happened. My Mother died prematurely because of the HCV
- 45. In the years towards her death my Mother became very self conscious of her appearance, especially the swelling to her face and stomach.
- 46. I produce Thirteen (13) photographs of my mother taken from the time she was in hospital for her Knee operation at the time of her 50<sup>th</sup>

Birthday and subsequent photos showing how the illness had affected her and the change in her appearance. **Exhibit WIT0714006**.

### **Statement of Truth**

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