Witness Name: Graham R. Cooksley

Statement No. WITN6870001

Exhibits: WITN6870002 – WITN6870003

Dated: \_\_\_\_\_/\_\_\_/2021

#### **INFECTED BLOOD INQUIRY**

# WRITTEN WITNESS STATEMENT OF GRAHAM ROBERT COOKSLEY

I provide this statement in response to a request under Rule 9 of The Inquiry Rules 2006, dated 25<sup>th</sup> August, 2021.

I, Graham Robert Cooksley, will say as follows:-

# Section 1 - Introduction

- 1. My full name is Graham Robert Cooksley and I was born on GRO-C 1969.I live with my family in Devon at an address that is known to The Infected Blood Inquiry, and work for the local university.
- 2. Within this statement I intend to speak about my mother, Margaret Annetta Cooksley, who was born on GRO-C, 1936 and was, at the time of this statement having been provided, was eighty-five years of age. I am her only child.
- 3. My mother had initially intended to provide a witness statement to the Inquiry herself, but she has recently suffered a fall and broken an ankle, as a result of which she had to be hospitalised and undergo surgery. As a consequence, she is unable to provide a statement herself and I do so in lieu, but I have discussed the issues with her before having done so.

- 4. I intend to inform the inquiry of her having been infected with Hepatitis C (also referred to as Hep' C and / or HcV) as a direct result of her having used contaminated blood; and in particular the nature of the illness and how it affected her, the treatment she received, and its impact for her and our family.
- 5. I have made this statement without access to my mother's full medical records.
- 6. My mother and our family have not been involved in any previous litigation proceedings, be that in the United Kingdom or elsewhere (e.g. in the United States of America), and I have chosen not to secure legal representation at this point in time. The issue of anonymity and the approach of the Inquiry to anonymity has been explained to me by an Inquiry investigator as has the 'Right to Reply' process wherein were I to be critical of any particular individual, identifiable group or organisation, then they would have the right to reply to the same.
- 7. I provide this statement in the full knowledge and understanding that with the passage of time, memories can fade. I had been a child when my mother became infected and accordingly I am trying to recall events of many years ago when I was ill placed to note them myself. The information I provide comes from my mother and I, but I can only provide and use approximate timeframes based on life events, so I would suggest that they be regarded as 'near to' rather than 'precise' dates.
- 8. Having said that I have spoken to my mother about this, which I have, these are my recollections and not those of my mother. I have had some significant involvement in her care, supporting her attending appointments, being privy to discussion as to her condition and care for various health issues, but only of relatively recent times. Many of the events with which the Inquiry is concerned took place before my active inclusion and as such I had not been a party to discussions concerning them.

#### Section 2 - How Affected

- 9. My mother was one of three children, having both a brother and sister, and was born and brought up in a small village in Cornwall. She is a widow and lives alone, close to my wife and I, on the coast in Devon.
- 10. My mother is now retired, but over the years she had a variety of jobs, such as her having been an auxiliary nurse or cleaner, but she was primarily a housewife. Her last job ended in 1990 when she had been working in a printworks. She is now retired.
- 11. My mother was always an active, outgoing woman, fit and very much 'busy' all of the time. She had been a member of the Women's Auxiliary Airforce and had worked as a nursing auxiliary in a number of hospitals across the Plymouth area. She was a lady who enjoyed life and could never have been regarded as having been anything of a 'wallflower' as he had a real zest for life.
- 12. My parents met at a ballroom in Plymouth where they married and lived throughout their lives together. My father had been an only child who came from North Devon and was born in 1932 my mother was his second marriage.
- 13. I was born in 1969 and am now aware that my birth was anything but ordinary as my mother suffered complications immediately following my birth and ended up having had to have a hysterectomy. I don't know the full 'ins and outs' of this situation, suffice to say that I believe she had to have the hysterectomy following my birth, there was no option for her not to have this surgery, and that during the course of either my birth and / or the hysterectomy, she had to be given a blood transfusion.
- 14. I can't remember, and don't actually know when this all happened exactly, but I had been a sickly baby and required surgery myself when I had been around six months old I believe that my mother's hysterectomy operation was conducted soon after that, so it would have been in early 1970.

- 15. I do not know how much, if any, information patients were given regarding medical intervention at that time, be that in childbirth (1969) or when facing a hysterectomy operation (197); for example, whether or not any form of information would be given 'up front' as regards the likelihood of a blood transfusion being necessary. For all I know it may have been a matter of routine for blood to be available for use at childbirth and / or for a hysterectomy operation, and it may not even have been discussed.
- 16. In so far as I am aware, there are no other occasions when medical intervention or treatment of my mother saw her being given any blood by transfusion or blood products this or these were the only occasions. My mother was not a person whose lifestyle placed her at risk of Hepatitis C infection from any other source, such as drug abuse, self-inflicted tattoos or promiscuous sexual activity, so a blood transfusion, for us, is the only likely source.
- 17. However, I cannot rule out the fact that whilst working as a nursing auxiliary, she may have experienced a needlestick incident, although I am unsure of what her actual duties were and what her exposure to risk may have been in that regard, if any.
- 18. Discussing the cause of her infection with her recently, she appears to have some recollection of a staffroom needlestick injury at the Devonport Hospital. On this occasion she had put a hand behind a sofa only to jab herself in the hand on a needle that had been left there.
- 19. Whilst growing up, I remember that my mother regularly suffered minor health problems requiring medication and am told that this had always been the case, certainly from her early 20's. She was also rather accident prone, such as one occasion when she fell off of a moped and broke her wrist.

- 20. As the 1970's progressed and she entered her forties, she began to experience the menopause. We'd go away as a family on holiday, and end up spending time in a local Accident & Emergency Department as she would suffer a fall and sprain or break something. There was a perception of her being clumsy or accident prone and menopause related issues didn't help as she just always seemed to be having issues of some firm or another.
- 21. By the late 1970's, the trips and falls she was experiencing had become ever more frequent, as had the broken bones repaired in A&E. She was treated in various hospitals or clinics across the country, appearing to have particularly hard luck whist we were on holiday.
- 22. My mother's own General Practitioner (G.P.) in the 1970's was a Dr. Lawson until she changed to a group practise surgery on Glendower Road in Peverell (Plymouth). Of more recent years she has been treated through the Lisson Grove Surgery on Mutley Plain (Plymouth), but we have never sought to secure her medical records from any of these, or from any of the hospitals she attended.
- 23. By the late 1980's and into the 1990's, my mother was probably experiencing her best years in health terms, but my father's health was then going steadily downhill. Heart problems which had first started in the 1970's had got progressively worse and in 1990 he was given six months to live, so grave was his condition. Fortunately, he managed to carry on for a further five years, eventually passing away in 1995.
- 24. I lived at home until 1993 when I married and moved out. Following her retirement (1990), my mother had been caring for my father, but with him passing away just a couple of year later, she was left living alone.
- 25. I am not proud of the situation, but there was a period of time during which my mother and I weren't speaking to one another. I felt that she had been against my wife and I having a second child and we fell out as a result. This would have been between 1999 and 2002 when we only occasionally spoke to one another through an aunt, we didn't communicate directly.

- 26. My wife and I experienced some difficulties with second our daughters birth, issues which somehow got back to my mother and then slowly, as of 2001 to 2002 we started to get back in touch with one another and rekindle our relationship.
- 27. My mother had not only been 'clumsy' but had also suffered problems with her sight as a result of her having had scooter accidents in particular. In so far as I can recall, there were always ongoing preventative measures being taken in so far as her sight was concerned for example she never drove, for safety's sake. Over time the deterioration of her eyesight became ever more prominent and she underwent a number of eye operations, with varying success. In the end she lost her right eye which is removed and is now glass.
- 28. The surgery to remove her eye took place in 2003 2004 at a specialist eye hospital in Plymouth (The Royal Eye Infirmary) which was a very old hospital going in was stepping back into the 1960's, but I am not aware of her ever having had to have whole blood or blood products related to any eye operation.
- 29. Over the period of our having been estranged, mother moved out of the family home of many years and into a warden controlled flat the result of her deteriorating eyesight where as she had been told that she would go blind at some point in time, she wanted to get into a suitable environment before she lost her vision entirely. She was only in her sixties, and the youngest to have moved into those retirement flats.
- 30. With our no longer being estranged, I remember my mother telling me about various ailments she was experiencing and a feeling of 'things' being wrong with her health. I can also distinctly recall having seen a major difference in her overall physical appearance there was a noticeable deterioration in her condition and appearance.

- 31. Even in photographs from around the time of our daughter's birth (our first child), prior to our falling out, she had looked quite old in part as she was from a generation who dress with an old outlook and as such may have looked older than she actually was but by the time we'd built bridges, she had physically aged, and aged beyond the couple of years we'd been apart.
- 32. Initially we put this down to the stress of her situation and the move, both of which would have taken their toll, and she spoke of a number of moans and groans but we didn't think too much of it, she looked older and was ageing, wwe didn't think that there was anything else going on.
- 33. Other health issues also arose, which may have served to cloud our appreciation of what was actually going on, for example she was found to have developed Type II Diabetes following a number of appointments and tests.
- 34. Between 2005 and 2006 my wife and I started to notice that my mother's skin had become very 'thin' and that she was bruising easily. At the same time she often complained of suffering stomach pains or of bloating. She was having lots of trips to the GP's or clinic and was taking a lot of medication at the time, which may not have helped with these conditions.
- 35. My mother is also very hard of hearing, although she has become very good at lip reading in order to get by. Of recent times this has made things very difficult for her with everyone having to wear masks, due to Covid-19, so she would simply give you the impression that she has understood, then guess the answer if she hadn't heard a question.
- 36. As a result, I now always go with her to any appointments she may have, as a second pair of ears and eyes and check if she can hear and / or has understood what may have been being said. She is mentally sound, as sharp as a pin, but her hearing and eyesight are failing so she needs help.

- 37. In 2010, my mother spent about four months in a number of Plymouth hospitals, but I cannot now recall what the cause was of her first having been admitted, possibly a fall, but I cannot now remember. This came at a time when her diabetes was wildly out of control and I believe that she was also suffering with issues affecting her liver.
- 38. She was admitted to Derriford Hospital in around March 2010 and wasn't released until October. Prior to this, her health had been progressively worsening for about four years and she'd been having regular blood tests every two months or so and had had scans taken of her liver.
- 39. Now talking with the benefit of hindsight, it is evident that Hepatitis C infection was coming to the fore over this period, but it was not identified at the time so it just strengthened as she weakened from it.
- 40. It wasn't until around 2005 that she was tested specifically for Hepatitis C, I think we had to go to the hospital to get the results of the blood test, so I accompanied her for an outpatients' appointment. She was told that the test was positive, she had HcV.
- 41. I do not know how many tests would have been performed on blood taken from my mother leading up to this point in time, but there were lots and with the benefit of hindsight, lots of opportunities missed for Hep' C to have been diagnosed. In the interim, her frequent bouts of illness had been attributed to all manner of things, even the menopause, but not what they actually were.

## Section 3 - Other Infections

42. I do not know of any other infections she may have contracted or been exposed to as a result of having used contaminated blood.

#### Section 4 - Consent

43. I cannot comment, because I do not know, what consent my mother may or may not have been asked to provide regarding any historic treatment or tests. All I can say is that she is a very trusting woman, particularly trusting as regards the medical profession which she holds in the highest regard as a consequence of which she would tend to have gone along with whatever she may have been being told or asked to do, by doctors – in her view, 'Doctor knows best.'

#### Section 5 - Impact

- 44. My mother was not diagnosed as having Hepatitis C until quite late in her life, so the impact in terms of how she has reacted to the news and its impact upon her in non-medical terms may not have been so great as it could have been had it been diagnosed much earlier, when perhaps it should have been.
- 45. In the interim, she suffered from all of what I now believe to have been classic symptoms of Hep' C infection, she often found herself feeling extremely tired, but without any apparent cause; she was lethargic, which was out of character for her; she experienced lots of unexplained general aches and pains; often had or felt as if she had flu; she appeared jaundiced on occasions and had a bloated stomach.
- 46. Many of the issues she faced, as detailed above, were simply attributed t the menopause, or to her ageing, the latter especially so in my case, but fortunately my wife encouraged me to pursue it further as 'something wasn't right.'
- 47. This led to her having been found to have Hepatitis C. Not only was she told that she had the infection, but I was told that I too could have caught it, through her, as it had apparently been present for many, many years.

- 48. This worried me, not only for my own sake, but for that of my wife and my own children if I had caught it from my mother, who hadn't known that she had it, could I have passed it on, unwittingly, myself? My wife and I were really concerned at this prospect, so I was also tested and we found it a very worrying time as I awaited the result. The test was conducted soon after hers, and fortunately came back negative.
- 49. Alongside other problems, in particular her deteriorating eyesight and hearing, Hepatitis C infection and its various symptoms served to impede my mother's social interaction. My mother had always been a rather volatile character, but HcV appears to have exacerbated this trait as her mood swings could lead from her being seen as a cute old granny one moment to us having to tread on eggshells the next for fear of incurring her wrath.
- 50. My mother used to be a very independent person, and would happily do things like take herself off, with her sister, on coach trips around Europe, but slowly these sort of excursions dwindled and then stopped altogether, and even local trips, to the park or shopping, have all but ceased now.
- 51. My mother, wife and I also find it quite distressing to have to tell other people of her HcV status even ambulance personnel attending her have to be told, and it's not what you would expect to hear with a lady of her age, so we find it an unpleasant necessity.
- 52. My mother is now a walking encyclopaedia of medical ailments, with both the symptoms connected to Hepatitis C infection and other issues she faces such as diabetes. All the same, she herself appears far more concerned with the day to day issues she has to address, especially her failing eyesight and falls, as opposed to Hep' C.

## Section 6 - Treatment / Care / Support

- 53. When my mother was diagnosed as having hepatitis C, we weren't given a lot of information. I believe that she received some sort of handout a photocopied A4 sheet of paper with some information on it, but nothing more. My mother doesn't use the internet, but I was able to sit with her and we researched the condition together to flesh out the basic information we had received.
- 54. Having been diagnosed, my mother began having regular ultrasound scans and also had to have biopsies performed together with frequent blood tests. We were told that her condition would be monitored every three months, and she had been found to have what was described as 'scarring' on her liver, its function having been impaired.
- 55. My mother had by then been taking a large number of varying medications, including steroids, over a lengthy period. When she had been diagnosed, my mother and I were given the impression, albeit implied rather than direct, that at some stage she would be put onto a course of treatment for HcV. We were told of certain drugs which were available, not that I can recall their names now, but in any event she has never received any treatment for Hepatitis C and simply has to manage and live with the condition. In short, she has been offered treatment to manage HcV infection but not to tackle the infection itself.
- 56. I do not know if Hepatitis C infection has played any role in any of her other, apparently unrelated, problems, such as her recently broken ankle, and it has been most frustrating, that with the Covid-19 restrictions which hospitals have introduced, it has become very difficult to access clinical specialists to explore this. Tests have revealed that my mother has also seen a decline in the function of her kidneys, which may or may not be related, but again we can't access anyone to take it any further.

57. My mother's quarterly Hepatitis C monitoring appointments have been reduced over recent years and are now six monthly but these are now no more than a 'phone call (again a result of Covid-19) which is far from ideal, especially taking into account her hearing difficulties. But her Hep' C appointments are not alone in this, over the past eighteen months she has had just one face-to-face clinic consultation.

### Section 7 - Financial Assistance

- 58. My mother has never sought any form of compensation or financial assistance from any trust or fund established to assist people infected with HcV through contaminated blood / contaminated blood product use and I know, from conversations I have had with her, that she does not want to make a claim.
- 59. As a result, neither my mother or I have ever sought copies of her medical records.
- 60. My mother and I were unaware of the Infected Blood Inquiry until such time as we received a letter from Derriford Hospital informing us that her details had been passed to the Inquiry, since which time we have come forward to provide a statement.
- 61. Her details were passed on as she had previously been asked to participate in a research project, as a patient with HcV, by HcV Research UK (or HCVRUK as they are also known). She had originally been referred to this group by the South West Liver Group (who are based at the Derriford Hospital) and had willingly taken part in their study.
- 62. In so far as my mother was concerned, the study in which she was concerned, commenced in April 2012. As a research initiative, the issue of consent was clearly of some concern as those running the programme required quite detailed written consent, which she willingly provided.

#### Section 8 - Other Issues

- 63. I am led to believe that my mother is unlikely to be able to substantiate any claim made with the England Infected Blood Support Scheme (or EIBSS) in the absence of any medical records, and as she is unable to definitively say when and where she received a blood transfusion, although she believes this to have been the case, and we believe it to be the only possible source of her infection with Hepatitis C.
- 64. My mother and I believe that she was most probably given a transfusion of whole blood, in 1970, when she underwent a hysterectomy operation following problems she experienced following my birth in 1969; although she has undergone a large number of surgical procedures since that time, none are known to have involved the use of blood or blood products, albeit that this cannot be ruled out.
- 65. In order to assist the Infected Blood Inquiry, and in particular concerning the issue of consent and how it may have been addressed at various times and by different bodies, I now produce a letter received by my mother as regards consent and a form of consent as completed by my mother for the HCVRUK, as exhibits:-

EXHIBIT WITN6870002 A letter dated 12/04/2012 from Sally Read,

Hepatology Research Nurse, Plymouth Hospitals NHS Trust (S.W. Liver Unit,

Derriford Hospital)

EXHIBIT WITN6870003 A form of consent as regards participation in

and CVRUK research project dated

11/04/2012

# **Statement Of Truth**

I believe that the facts stated in t	this witness statement are	true
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	GRO-C	
Signed:		
Dated:	15/2/2021	-