Witness Name: Margaret Mary Clark
Statement No.: WITN2671001
Exhibits:
Dated: 7th November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARGARET MARY CLARK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8th November 2018. I adopt the paragraph number in the Rule 9 request for ease of reference.

I Margaret Mary Clark, will say as follows:

Section 1. Introduction

My name is Margaret Mary Clark. My date of birth is the GRO-C 1949 and my address is known to the Inquiry. I am semi-retired, but when I am working I am a counsellor. I am currently living alone. I intend to speak about my daughter Melanie Richmond's infection of Hepatitis C which she contracted through receiving Factor VIII in 1990. I will speak about in particular, the nature of her infection and how the infection affected the treatment she received and the impact it had on our family.

Section 2. How Affected

Nature of my daughter's original condition

a. My daughter was diagnosed with Von Willebrands disease. It is a bleeding disorder. She was diagnosed with this as a young child, when she was about 4 years old which would have been 1975. The doctors started investigations because she was developing serious bruises, when she was about 2 years old. This was when we lived in Dubai. GRO-C GRO-C ultimately she was diagnosed with Von Willebrands disease when she was 4. We moved to Scotland in 1979 from Dubai when she was about 7 or 8 years old. When my daughter required treatment for her bleeds she would receive Tranexamic acid and DDAVP. She would receive this treatment if she had any dental treatment or minor cuts. She would usually receive these treatments two or three times a year. These treatments were always successful.

How my daughter was infected

My daughter has Von Willebrand's disease which is a bleeding disorder.

GRO-C

b. In 1990, when my daughter was 19 years old, she had a period of time where she was required to be admitted to the Aberdeen Royal Infirmary Hospital for treatment. Despite the fact that the Tranexamic acid and DDAVP treatments had always been successful in the past, she was given Factor VIII. This was the only infusion of Factor VIII that she ever received. It was this treatment that contained the infection. My daughter and I were unaware she had been given this treatment until after she received it. The first time we became aware of this was when Dr Audrey Dawson spoke with my daughter and advised her that she had been given Factor VIII. The Dr made the comment "*Lets hope that there was nothing nasty in it*" referring to the Factor VIII. I remember saying to Dr Dawson "*What do you mean*?" and she didn't answer me properly. She just said *"We will have to wait and see, it will take about 8 weeks."* She then disappeared off with no further information. I remember thinking "*What did she mean by saying a potential something nasty?"*

c. My daughter was under the care of Aberdeen Royal Infirmary at the time and was under the care of Dr Audrey Dawson who was a Haematologist at the hospital and under the care of Dr Bennett who was a Haematologist at Aberdeen Royal Infirmary as well. Dr Dawson would have been the doctor who prescribed the infected Factor VIII.

d. My daughter received this infected product, once in 1990. I cannot recall which month it was.

Information and advice about the risk of infection

a. Nobody told us about the risks of Factor VIII. We weren't even told she was going to be treated with this product until after it was given to her. We would have liked to have known about the potential risk of this beforehand. It would have allowed my daughter to have made an informed decision about her treatment. The other blood products historically had always been acceptable, therefore we do not understand why this was suddenly changed and no explanation has ever been provided. Our daughter would have never agreed to this treatment had she known about the risk. She should have been given the option and I want to know why she was not given the option. I want to know why Dr Dawson did not give her any information nor discuss matters with her.

Finding out about infection

b. My daughter was admitted into hospital in 1990. I cannot recall the month or even the time of year. Melanie will know this information, and it will be in her medical records. After this night where my daughter received Factor VIII we did our own investigations into what Dr Dawson may have been referring to in her offhand comment. I think the hospital did do a test for this shortly after our daughter received Factor VIII, but she never heard anything back from the hospital. I made further enquiries that night. I chased Dr Dawson down the corridor and I kept asking her to clarify what she meant. She just kept saying *"We will wait and see, we will test her blood in a few weeks*". Later on my daughter was in hospital again for a nose bleed, she was always in hospital for something. I cannot recall the date this took place it was so frequent. Dr Dawson had gone into her ward and said to Melanie, *"Make sure you dispose of that tissue in the yellow bin"*, referring to a tissue that Melanie was holding. It was to be put in a bin for contaminated waste. My daughter asked why? Dr Dawson then said to her, "*Well because you have hepatitis C*. This was said in quite a vicious tone. This was done in the ward in front of everyone. Dr Dawson is a very angry person and she was not easy to talk to at that time. My daughter was extremely upset. Neither of us knew what this meant. The doctors didn't know the long term prospects for Melanie's health. My question has always been, if they knew it was contaminated, why was my daughter not given the option about her treatment? She was over 18 and should have had the conversation with the doctors. We only saw Dr Dawson a few times after this and we never saw her again to put this question to her. Looking back, it was a time where doctors were not questioned at all, now it is a different story, you question everything. I only realized hepatitis C could kill a person when I saw a television documentary in

GRO-C

1993. After diagnosis when she attended hospital, the staff would be very quiet about the matter. There was no kindness and no proper care.

Information and advice about the infection

c.Dr GRO-D provided my daughter and I with a little bit of information after she was diagnosed. He spoke with us but couldn't really tell us how it would affect her in the long term. It was a documentary that told us how dangerous the infection was.

d.Dr GRO-D really just gave us practical information. The information he provided was about how to take care with things like hygiene to ensure nobody else caught it. There was nothing else. I remember we tried to find out information ourselves. We came across a leaflet about the infection. Even this didn't state how dangerous it was. All my daughter can recall is that suddenly the nurses all wore masks when they treated her and she had no idea why this was required. No medical professional explained to her why they felt this precaution was necessary. She felt like a leper then and often feels like a leper to this day. I had a beautiful daughter and this awful thing had happened to her. We could not make sense of it.

Information about the risk of infecting others

e. My daughter may have been provided with information about the risk of spreading the infection at an appointment. I was not at this appointment however so I am unaware of details of this conversation.

3. Other infections

My daughter received a letter at some point which advised her that there was a chance that she was infected with variant CJD due to the Factor VIII that she had received.

My daughter had a lot of stomach problems and needed an endoscopy in 2007 to take a look at what was going on. The local hospital refused as they wouldn't use their equipment on her. This was because there was a possibility that she had contracted variant CJD. There is no test to confirm this accurately so as a safety measure hospitals are required to incinerate surgical equipment that is used on her. Therefore, they refused to do the endoscopy. She began to get worse and no hospital would treat her or use their equipment to investigate. We tried to attend St George's Hospital in London, however they also refused to use their equipment. We ended up flying up to Aberdeen. I went to the hospital and said to them, that they were the ones that had infected her, so could they please treat her. They refused. We went to see the SNP for help, they said they could not do anything and refused to help further. We flew back to England and saw our own MP who was Jeremy Hunt at the time. He wrote to our local hospital at Frimley Park Hospital, Camberley, saying that this was disgraceful and that she needed to be treated. Jeremy Hunt really tried very hard to help at this point. We went back to the hospital in Frimley Park and they were extremely angry with us for having contacted Mr Hunt. There was a terrible atmosphere, however they did check her with a little disposable camera which passed through her. When this happened they found that she was in a terrible mess. My daughter was then taken into hospital and had to have some of her bowels removed because matters had been left for so long by this point. She had to have a bag fitted, which was reversed three years later. That was a terrible experience.

Section 4. Consent

a. My daughter was tested without her knowledge when she was tested for Hepatitis C by Aberdeen Royal Infirmary. She was also given Factor VIII without her knowledge in 1990. She would have been 19 years old when this occurred. It was shortly after she received Factor VIII in 1990 and when

GRO-C

she was tested for this. She was tested several weeks after she received the product. This has to be the case because she was not told she was being tested for hepatitis C, she was just told she had it.

b. The hospital did not seek my daughter's consent to treat her with Factor VIII. I want to understand why they would not ask her first. My daughter would have to tell you more about the consent process or the lack of it.

c. She was definitely treated without being given adequate of full information when she received the Factor VIII. When I got to the Aberdeen Royal Infirmary after my daughter found out she had been infected, she was in total shock. She didn't know what it meant. She didn't know anything about the infection. At the point when she received the Factor VIII, she couldn't understand why she had received this when her other treatment had historically worked so well. My daughter did ask Dr Dawson about this and Dr Dawson did say then that the reason she had been given Factor VIII was because my daughter had bumped her head. Dr Dawson was concerned that there may have been an internal bleed. This was the only information that was given to my daughter later on. My daughter had no idea what hepatitis C was or any details about it at all.

d. I cannot say if she has been tested or treated on for the purposes of research.

Section 5. Impact

a. When she was first infected we had no idea what hepatitis C was or what it meant for our daughter. We put it to the back of our minds, however, she got so lethargic and she lost all her zest for life. She just wanted to stay in bed all the time or she would sit at the kitchen table with her head down. We could see she was depressed and tired all the time. That was when we could see there was something wrong with her. She tried to hold down a job but she couldn't as she would just get exhausted. She worked for a period of time in a school with children with learning disabilities but she was always dragging herself around and I would find her exhausted constantly. It made her incredibly depressed trying to work and being unable. At one point she took on a job as a hostess on a bus tour between Scotland and England. She did this because it meant she could sit down. Even this though was too much. This was throughout the 1990's up until the 2000's. I cannot be more specific than this. She kept trying to live her life but had to fight every day. She then got married but she struggled all the time. She gave birth to her first two boys GRO-D She was a single parent from 1996 - 2012. She had her youngest son with her current partner and she moved in with her current partner in 2012. She was never in a position to work and ultimately there was no money or support until 2012. We supported her almost totally. She was given some benefits but then these benefits were stopped so we had to keep paying all her bills. I don't remember when her benefits started and stopped. There always seemed to be a problem with proving anything to the benefits people. She started on benefits GRO-D only because she was a single mother. I really cannot recall dates and do not want to give incorrect information. I remember at one point she told the benefits people that she was going to visit her father in Bournemouth, and they wrote down that she was going on holiday. They said if she was well enough for a holiday she was not disabled. She ultimately started to do fostering as she was able to be paid for this but was still able to rest during the day, if required.

b. There was the possibility of variant CJD as described above. My daughter did develop Chronic fatigue syndrome. This would cause her to 'crash' suddenly which might put her in bed for a day or two. She couldn't' get a job, because she couldn't 'guarantee that she could be there to work. She was living on her own when this happened. Her marriage had broken down after she was diagnosed with Hepatitis C. She was married at 20 and she was suffering from depression and exhaustion before they even found out about the existence of the hepatitis C.

c. My daughter was not given the treatment for Hepatitis C for a long time because she had the worst type of Hepatitis, Geno type 1A, which was considered untreatable. After a long time, the doctors

GRO-C

said they were going to give her treatment for 3 months to see if this made a difference to her or not. It was deemed that if this worked she would be given a further 3 months of treatment. This was in 2007. The treatment took place in Frimley Hospital, Frimley. I don't know any names of the doctors. She became ill straight away from the treatment. She was already exhausted so it was even worse when she started treatment. We had been warned beforehand that this would be the case and when it was clear it would be too much for her, we all decided that her 3 children should come and live with my husband and I as a result. The boys were 3, 7 and 10 years old. I remember that straight away the youngest wanted to go home to his mum. We couldn't' take him home as his mum was too ill. She was totally exhausted. The youngest pleaded with me, I remember he was in the seat of a supermarket trolley and he was sitting up and he reached up to me to pull my face towards him. He said "*Grandma please take me home to Mummy!*" and I couldn't explain to him why that was not possible. It was heart breaking. He started to get very difficult because he was desperate to go home. It was a great strain on my marriage. GRO-D. It ultimately contributed to the end of our marriage. My daughter was very poorly then, she was sick all the time, and she spent the days in her bed.

The doctors then discovered that the treatment was having a good effect. They told her to keep going for another 6 months. She was very ill on it. Ultimately the children stayed with us for 14 months. At the point she did regain some strength, it was deemed that she could take two of the children home. She couldn't cope with all 3 of them at once though. I kept the middle child with me. He has Asperger's syndrome so we wanted to keep him as settled as possible. He lived with me for 6 years. I have no doubt this would not have happened had my daughter not been infected with Hepatitis C.

d. She received Interferon and Ribavirin treatment for the Hepatitis C. When she first started this treatment, she was not fat but she was quite solid. I remember that the levels of treatment were calculated according to her weight at the time. As she continued on with the treatment, her weight went right down. She was a tiny skeleton at one point and she was still on the same level of treatment. In the end, a hospital pharmacist asked her about the amount of drugs she was on and only then were the levels altered. She got very ill. At one point we thought she was going to die because of the treatment.

e. I cannot think of any other time when she has not had the treatment she has needed other than what I describe above. The only other times she didn't get the treatment she needed, were the times she was too ill to receive it.

f. I can only think of the time when we couldn't' get the investigations and treatment for her stomach because the hospital refused on the basis that she may have variant CJD. Details of this are described under section 3. The only other point I have to add to this is that the hospitals received a letter which indicated she "may" have CJD as well as hepatitis C. Once the hospitals received this letter they wouldn't use their equipment on her for business reasons. They would have to incinerate the equipment if they did and this was not economically realistic. This caused us to contact Jeremy Hunt as I describe above.

g. My daughter was very depressed, very down and I particularly remember one time when she was bleeding very badly in the bathroom. GRO-C GRO-C She was so exhausted and run down. GRO-C GRO-C She phoned the hospital during this bleed and said that she was not coping. Nobody at the hospital did anything. There was no offer of mental health support at all. I want to know why this was? Why did my daughter nor receive support and care when she was infected by a product that was not her fault?

h. There might have been an impact on other medical or dental treatments. I am unsure. She did often get hospitalized and she was aware that the staff at hospital always appeared to presume she was a junkie which made her feel terrible. My daughter has never consumed alcohol before. There

GRO-C

was a time when the hospital staff actually removed the hand gel from the end of her bed because they thought she might drink it. They thought because she had Hepatitis C that she could be an alcoholic. There was always an atmosphere when she was in hospital and it was horrible.

My daughter recalls telling her child's teacher about the diagnosis. This was before she became properly aware of the stigma around the infection. She then went to a parent, teacher meeting. At this meeting, all the parents sat down and were given cups of tea in china cups. My daughter was not offered a china cup and she was given a paper cup. The teachers said to her that they did not want to pass the hepatitis onto other people. GRO-C GRO-C Her mental health was not great even before the hepatitis C. When she was diagnosed with hepatitis C she felt dirty. She was a little bit naïve about the way other people would respond and she had told the school that she had been too poorly to pick the boys up from school and explained why. She was in complete tears after this incident with the paper cup. She didn't stay, she left and went home. She felt very bad about herself after this, much worse than before. I felt absolutely heartbroken for her. She was the only person in our family who has Von Willebrands which in itself is bad enough. She doesn't tell anyone now; she has been cleared of the virus so it shouldn't be an issue. She did attend hospital at Frimley Park after she had been cleared of the virus and the doctor misread her notes and diagnosed her again. She phoned me up screaming "*It's come back"!* That was a devastating experience. I remember that day because my older son was diagnosed as being terminally ill that day as well. By the time, 2 days later, the mistake was rectified, the damage had been done. We were all traumatised by this. There will be other instances and yes they were frequent, but my daughter will have to tell you about them herself.

The children did very well through everything, but it was extremely hard on them. They were happy at first staying with me but after a period of time they were worried about their mum. They were all quite naughty. I remember thinking that I couldn't cope during this period but I had to for my daughter. I had to be very strict and it was not easy. GRO-C GRO-C GRO-C There is no doubt that the children, my husband and I were all traumatised and struggled to cope with what happened.

Further Impact

a. My daughter was unable to work at all. She was very poorly and was unable to get herself into a position where she could work continuously. Eventually she managed to arrange to do some fostering which allowed her to rest in the day. For a very long time as I describe above, I had to pay most of her bills and she did at points completely financially rely on my husband and on me.

b. When I agreed to look after the boys, I couldn't work at all. I was a full time carer for them. As she began to get a bit better the boys were able to visit her a little but I was still unable to return to any sort of employment for a long time. I was a self-employed counsellor. I stopped work for 14 months when I had to watch all 3 boys. I started slowly again after this. I cannot recall specific dates now about this because it was so long ago. There was a period of time that I had to take updated courses before I could see clients again which made it a very long return to work process. This was a big financial strain. I was a self-employed counsellor, so when I did return to work it took a very long time to build up my clientele again and I had to undergo retraining before professionally starting up again.

Section 6. Treatment/Care/Support

The difficulties that my daughter has experienced with treatments as a consequence of being infected are described above. There was no psychological support for my daughter and none for our family. We didn't even know there were other families like us in our position. We felt isolated and alone. It was very

GRO-C

inadequate in terms of support. It was an eye opener when we did realise that there were many other families in the same position as us. I had a poorly son who subsequently died which was very difficult. I felt I was not able to see him as much as I wanted because my daughter was ill which is very upsetting. Our son had diabetes all his life and he got a bug in 2010. It was not salmonella but it was similar. We nearly lost him then but he pulled through, however he never regained full kidney function again. He struggled on until the 23rd January 2014 when he passed away. I was constantly going between looking after Melanie and my son who lived further away in the South of England. His name was Timothy Clark but he changed his name because of all of this to "Lester Corral". This was an anagram of rollercoaster. He felt like his life had so many ups and downs, that it was fitting.

Section 7. Financial Assistance

a. I don't know how my daughter was informed about the financial assistance available. She is a member of the Haemophilia Society so it may have been through them. You would need to ask my daughter.

b. My daughter received a 1st payment from the Skipton Fund maybe about 10 years ago and then a 2nd payment roughly about 18 months ago from the Skipton fund. I am unsure about the amounts.

c. I think my daughter had to fill out forms to apply for the Skipton fund. I am unsure.

d. I am aware that my daughter felt demeaned an embarrassed applying for financial assistance all the time. I am unsure on further difficulties in relation to the Skipton Fund. I am aware of a lot of troubles she had around her benefits and trouble she had receiving support from the benefits department. Melanie has received a letter recently from the SBISS advising she will be getting a monthly payment from December every month. She has never applied to this. They wrote to her out of the blue. This will be a big help. I don't know a lot of details around her benefits. I don't want to pry into this, I just know that we supported her financially for many years. She would have to advise on this issue in more detail. We stopped financially supporting her about 5 years ago when she moved in with her current partner who was able to take over this aspect of matters.

e. I don't know if there were any.

f. I know that when I had the 3 boys I asked for support from social services because there was no help elsewhere. I asked if there was anyway someone could help me or even employ someone to help. They laughed at me. Zero help. The financial burden was immense. I had to take money out my husband's pay cheque without him being aware to support my daughter.

Section 8. Other Issues

My daughter may have further documents to provide. I do not have further documents to provide.

Statement of Truth

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

Signed GRO-C

Dated 30/11/2018