

Witness Name: Michelle Tolley

Statement No.: WITN0276001

Exhibits: **WITN0276002 - 3**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MICHELLE TOLLEY

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

I, Michelle Tolley, will say as follows: -

Section 1. Introduction

1. My name is Michelle Tolley. My date of birth and address are known to the Inquiry. I run a support group called Contaminated Whole Blood UK, which has 226 members. I have been married for 34 years, with four adult children

and a sixth grandchild on the way. I have lived in Norfolk for eight and a half years, and was living in Clacton-on-Sea for 18 years before that. I have been medically retired since June 2016, and my husband also stopped working to look after me in early 2016.

2. I intend to speak about my infection with hepatitis C. In particular, I will speak about the nature of my illness, how the illness affected me, the treatment received and the impact it had on myself, my family and our lives together.

Section 2. How Infected

3. I was infected with hepatitis C when I received blood transfusions after giving birth to my children in the late 80s and early 90s. I received blood transfusions on at least two occasions, so I cannot be sure which transfusion was the one that infected me. All of my blood transfusions were received at Barking Maternity Hospital in Barking, Essex.
4. I gave birth to my eldest child on GRO-C 1987 on Shaw Ward at Barking Maternity Hospital in Essex. At that time, I had pre-eclampsia and had to be induced into labour five times. Eventually, my son was born just one day late. He was a big baby weighing GRO-C exactly.
5. I can remember being as white as a sheet after his birth. I could not stand up properly after he was born and remained in hospital for six days. A couple of days after his birth, I started haemorrhaging heavily and lost four units of blood. This necessitated a blood transfusion on GRO-C 1987.
6. Unfortunately I do not have my maternity records from this time, as they were destroyed very punctually after 25 years. However, I recall that the blood transfusion took about 16-18 hours. I had a bag of blood that I pushed

around with me, as I remained stubbornly independent even in my weakened state. The transfusion made me feel better because I felt like it was giving me back the energy that I had lost.

7. I gave birth to my second child on **GRO-C** 1989, again in Shaw Ward at Barking Maternity Hospital. Because my first child had been such a big baby, I was tested for gestational diabetes during my second pregnancy. This test took place on 24 October 1989 and came back with the result that I did indeed have gestational diabetes. My second child had to be born three weeks early because of this.

8. I lost 300ml of blood on this occasion so I was only given iron tablets rather than a blood transfusion. However, following my blood test for gestational diabetes on 24 October, I received a "blood card" from the North East Thames Regional Blood Transfusion Centre. I was the named holder on this card and it stated that "The serum of the above named contains atypical antibodies. Should this patient REQUIRE A BLOOD TRANSFUSION [sic], special care must be taken in cross matching the blood." I exhibit this card as WITN0276002 and WITN0276003.

9. I do not recall specifically whether any other information came with the card. I received the card by post, so a letter may have come with it. I did not know anything about the card or what it meant by "atypical antibodies". At that point, I just knew that I had to present that card if I needed blood. I did not know about non-A non-B hepatitis, as it was known then.

10. Six months after the birth of my second child, I became pregnant again, this time with twins. I remember that pregnancy as being awful throughout. I became very unwell and was constantly in and out of hospital with high blood pressure and protein in my urine. I eventually needed to have an emergency caesarean section because the twins stopped breathing.

11. For my emergency caesarean section, I was taken to the floor above the ward in which I had given birth to my other two children. That floor was completely closed off for finance and costing operations. The floor was unused at that time, but it did house another operating theatre, which is where the twins were born. I had to go up as it was still part of the maternity unit, and it may have been that the other operating theatre was already in use since my caesarean section was not planned.

12. The upstairs ward that I ended up in was completely closed off, shut. Again, I had slightly haemorrhaged even though the birth was by caesarean section so I had another blood transfusion. I am not entirely sure how much blood I received on this occasion; on my summary sheet it states "twins born, 1-2 units given at birth" but I remember having two units of blood after that. I am not sure whether the "at birth" comment refers to when I had the caesarean section, or when I received the units I remember around five or six days after the birth. The twins were born on GRO-C 1991.

13. After ten days in hospital, I was discharged and went home with my newborn twins. Then in 1992, we moved to Clacton-on-Sea and registered with a new doctor. Shortly after that in the early to mid-90's, I saw a programme or advert on TV discussing blood transfusions and the risk of transmitting hepatitis C. It advised people to call a helpline if they were experiencing certain symptoms and had received a blood transfusion before September 1991. At that time, I was already feeling very fatigued and was aware that I had received several blood transfusions prior to September 1991, so I called the helpline. They advised me to make an appointment to see my GP and sent me quarterly magazines.

14. I subsequently went to see my GP and requested a blood test as I was worried that I might have been exposed to hepatitis C. Unfortunately, I was turned away and was made to feel completely stupid for having such

concerns. When I explained to my GP about my exhaustion, he responded saying I had four young children so what did I expect? He completely dismissed my concerns about hepatitis C and instead made me feel like I'd wasted his appointment time. I trusted his judgement completely and thought that I was being stupid, because he was supposed to be the qualified health professional.

15. Between 1993 and 1995, I suffered from heavy bleeding when I was menstruating, and experienced a lot of pain in my abdominal area. I was then referred to Colchester County Hospital in 1995 to Mr Eddy for an investigation. When I attended the day unit, they informed me that they would set me up in a closed ward as the beds in the other wards were full. I did not think anything of the situation at the time, but it reminded me of being in the closed ward following the twins' birth. I was not given much information about the procedure, but the doctors did a dilation and curettage ("D&C") procedure, also known as a "scrape".
16. I do not recall precisely when, but at some point I was diagnosed with chronic fatigue. The doctors suspected that I had glandular fever, as I was constantly coughing and had other throat problems. I was very ill. My children had their six weeks of summer holidays at that time, and I was ill for the entire period whilst having to look after the children. I thought that I was just exhausted from being involved in many different activities – I supported the school as part of the Parent Teacher Association, and also worked with children who had behavioural problems. I thought that it was just natural for me to be tired.
17. Then in 2004, I was diagnosed with type 2 diabetes. I felt awful as I was suffering with so many different symptoms. I had stomach pains, gastric pains, an irritable bowel, neuropathy, fatigue, itchy skin, constant sweating, problems concentrating and difficulty remembering things. When I was

being tested for diabetes, my liver function tests showed that my liver enzymes were elevated above normal levels.

18. I had further liver function tests, again showing raised liver enzyme levels in 2009 or 2010. However, this went unnoticed and nothing was done about it. The results on these two separate occasions were not further investigated by the doctors. If further investigations had been made, I believe I would have been diagnosed with hepatitis C much earlier.
19. Unfortunately, it was not until November 2015 when I was told that I had hepatitis C. By that time I had changed to a different GP's surgery, this time in North Elmham, which had its own pharmacy. I attended the surgery in October 2015 for my annual diabetic blood test. At the same time, I also had very bad gastroenteritis: I was vomiting, I had lost five stone, I felt like I had constant flu, my skin was itchy, I had loose bowels and I was always either too hot or too cold. I initially put all of these symptoms down to the menopause, but then my symptoms got worse. I remember saying to my husband that I thought something was seriously wrong with me and that I was going to die.
20. After the surgery had taken my blood test, they called me back in to discuss the results. My GP informed me that my Glucose Tolerance Test ("GTT") results were much higher than normal – almost 600 when it should have been no more than 180. He then said he would have to ask me some lifestyle questions, and asked me whether I was an alcoholic. I said no, and informed him that I was losing weight but was needing more insulin, which was not normal. I then recalled that I had had two blood transfusions before the bloods were screened. I had a lightbulb moment when I made the connection between my uncontrollable blood sugar levels and the blood transfusions. The doctor did not ask me whether I had had blood transfusions; I recalled it myself when we were trying to work out the reasons why I had those blood test results.

21. Upon hearing that I had received blood transfusions before September 1991, the GP put his head in his hands. I told him that I had previously asked another GP to be tested for hepatitis C, but had been rudely dismissed. My new GP arranged for me to have a blood test the very same day.
22. I was at home when I received my blood test results. My new GP phoned me, and said that he was very sorry but I had hepatitis C. The news hit me very hard and I don't remember too many other details about how I responded, as I was already so ill at the time. My GP was very honest with me and told me that he did not know much about hepatitis C himself, but said that he was writing to the Norfolk and Norwich University Hospital for me to be seen there. He informed me that the blood test results showed that I had the antibodies for hepatitis C, but that I would need further tests in order to determine my genotype and viral load. He also gave me some information that he'd found on the internet regarding hepatitis C.
23. My GP was very good; he kept calling me in to the surgery for appointments with him. I suppose he was checking up on me and watching my state of mind following the devastating news that I had hepatitis C. He referred me to the Norfolk and Norwich University Hospital as promised, where I was seen quite quickly in early December 2015. My tests there confirmed that I had hepatitis C, genotype 1A with a viral load of 10 million.
24. I have no complaints against the GP surgery in North Elmham. However, I believe that there were plenty of missed opportunities where my infection with hepatitis C could have been detected a lot earlier, most notably when I requested a blood test in the mid 90's and was dismissed by my then GP. There were also subsequent occasions where my liver enzymes on my liver function tests were raised. Had these signs been noticed, I believe that I

would have been diagnosed with hepatitis C at a much earlier stage and would not have had to suffer such severe symptoms now.

Section 3. Other Infections

25. I do not believe that I have received any infections other than hepatitis C as a result of being given infected blood.

Section 4. Consent

26. I do not recall being asked to sign my consent for anything.
27. It was only later that I speculated whether I was subjected to experiments when I was taken to closed wards, once following the caesarean section and then afterwards for my D&C procedure.

Section 5. Impact

Physical effects of infection and treatments

28. As outlined above, I suffered many terrible physical effects as a result of being infected with hepatitis C. I lost weight dramatically without trying, I was in constant pain and was frequently vomiting. At first, the doctors thought that I also had pancreatic cancer or lymphoma in addition to the hepatitis. As a result, I underwent further procedures including scans, colonoscopies and endoscopies. This meant that I was constantly in and out of hospital, which of course was very draining in itself.
29. I had to wait six months to see a Hepatologist, which I was not happy about considering that I had already had to wait 28 years for a diagnosis. Then in

2015, the new Direct Action Antiviral drugs (“DAAs”) were introduced. These had fewer side effects than the older pegylated interferon treatment, but they were very expensive. The DAAs were gradually introduced, with priority being given to those with the most severe symptoms. At that time, I was undergoing so many different tests for different things that my fibroscan was overlooked. This oversight was only discovered by chance when the doctor mentioned to me that he couldn’t find the results of my fibroscan, to which I responded that they had not yet conducted a fibroscan for me. When I eventually had a fibroscan done in 2016, the readings showed that I had cirrhosis of the liver.

30. When my results came back with cirrhosis, I was informed that the hospital had to operate under certain guidelines imposed by the trust with the result that only eight people per month could be treated for cirrhosis on the new drugs. They told me that I warranted going on the list of people to be treated. However, shortly afterwards the hospital informed me that their funding had been withdrawn and that consequently, they could only treat two people per month.
31. I felt very angry when I heard this news, because I had already had to struggle in order to get myself onto the waiting list for medication. I was originally not supposed to be seeing a hepatologist for six months, so I contacted a staff member at the hospital, informed them that I was not prepared to wait six months, and got my waiting time cut down to three months.
32. When the funding was then withdrawn, I was very upset and turned to a local radio station to tell my story. I wanted the whole world to know how I had contracted hepatitis C. I did not feel stigmatised, rather I wanted to speak out and raise awareness of this scandal. The radio station asked me whether they could speak on my behalf. I said yes. Shortly afterwards, the funding for the treatment suddenly returned.

33. I began the six-month treatment of the AbbVie triple therapy regime in September 2016. The course of the treatment was thankfully successful. In March 2017, I was given the good news that the hepatitis C virus was undetectable. I had a sustained virologic response (“SVR”) which meant that I was officially clear of hepatitis C.
34. Although I am now thankfully clear of hepatitis C, the side effects of the treatment were terrible. The drug therapy included ribavirin; I had to take six ribavirin tablets every day for six months and it nearly killed me. Even though hepatitis C is no longer detectable in my blood, I feel worse now than I did before. I can no longer grow my hair out because of the drugs – it will always be short now and I sometimes feel embarrassed by my hair. I can also never donate blood as I have the antibodies for hepatitis C in my blood.

Mental effects of infection and treatments

35. Being infected with hepatitis C has severely affected me in terms of my mental wellbeing. I take medication now because I cannot cope with my life otherwise. The medicine I have is an anxiety relaxant rather than medication for depression; I have terrible anxiety because I feel like I’ve crammed thirty years of knowledge about hepatitis C into three. When I was first diagnosed with hepatitis C, I did not have a clue what it was or what it meant, how I had contracted it or why it had happened. After my diagnosis, my brain was like a sponge trying to soak up all of the knowledge and information about my infection, how it happened and why it was not diagnosed earlier.
36. Though I do not currently take antidepressants, I have also struggled with depression. I cannot help but relive some of my darkest days, or I will dream things and see things on TV that worry me about hepatitis C. I went through a very serious stage of just feeling completely useless in November 2015.

I felt like I was always letting people down because I could not work. I had nothing at all to give, so what was the point in me living? I struggled with serious suicidal thoughts and thought that I was going to die, because I simply could not see the point in me being alive.

37. Thankfully, I have my husband Dean and the support group I run, Contaminated Whole Blood UK, to keep me going. If I did not have their care and support, I do not think that I would still be alive.
38. I am clear of hepatitis C, but I now have to deal with check-ups every six months. I dread these scans, because I have to go into hospital every time and they take three to four weeks to write back. It is awful to be kept in suspense for that period of time as to whether there are any signs of Liver Cancer.
39. It is made worse by the fact that I know of people in my support group who have relapsed or had Liver transplants. Our former Admin secretary sadly passed away within a few weeks of the doctors finding something wrong with her liver. I dread that something similar will happen to me every time I go for a scan.
40. However, on some days the fact that I have the support group to run is my only motivation for getting out of bed. I do not want to let those people down. They support me and I support them. The emotionally draining nature of infection with hepatitis C is something that I do not believe the government will ever fully understand. It is exceptionally stressful and I often burst into tears for no apparent reason. I live in the knowledge that I am probably going to die of liver cancer, so I have made my own funeral arrangements. I should not have to do that.
41. My experiences with hepatitis C have also left me with a deep sense of mistrust in the medical profession. I do not want to believe in conspiracy theories, but it is sometimes difficult not to think that there was at least a cover-up.

Further medical complications resulting from the infection

42. I have suffered countless medical complications as a result of being infected with hepatitis C. For example, I had my gall bladder removed in June 2018, and prior to this operation I had to sign a declaration acknowledging that I was aware of the risk of bleeding to death on the operation table.

43. I also currently have some bleeding in my eyes, which is requiring a course of injections. I have had two of these injections already but have delayed receiving the third because I am so terrified and tired of having to deal with one thing after another. The injections I received are frightening because I had to have a needle in my eye whilst I was awake. The second injection was very painful, and the staff were talking aloud, asking one another whether they were using a batch of blunt needles. This awful experience has only fed into my fear and mistrust of the medical profession. In addition, I suffer from terrible stomach and abdominal pains. It became so bad in 2017 to the point that there were times where I could not go out. I was 52, and messing myself because I could not go to the toilet when I needed to. I was prescribed Creon 25000 which is a high strength pancreatic enzyme supplement, which are used by people whose bodies do not make enough of their own enzymes to digest their food Plus Colestyramine sachets to treat bile acid malabsorption. I also have to take Adcal - D3 calcium carbonate and vitamin D twice a day for the rest of my life. It feels like my medical problems are just never-ending.

44. Impact on medical or dental care for other conditions

While I was infected with hepatitis C, I was unwilling to go to the dentist because I did not want to risk infecting other people with the virus. In 1995, I suffered with bleeding gums and a sore mouth, which my GP diagnosed as gingivitis. Since I did not want to risk infecting other people at the dental surgery, I decided to try to manage the condition myself. I managed to pull eight of my own teeth out by hand.

Impact of infection on family and private life

45. My fear of cross-contamination naturally meant that I was most concerned about my own family. My children and husband had to be tested to ensure that they did not have hepatitis C. That was a really awful time for my family. My daughters were very concerned – they only told me then that they used to use my razor. My youngest daughter was especially worried about that. If they'd chosen to use my toothbrush, it would have meant I could have unknowingly transmitted the virus to them. Fortunately all of my family were clear, but I still worried and requested my husband Dean to be tested again after I was cleared of the virus, just to be sure that I had not passed it on to him in the meantime.
46. My infection with hepatitis C has unfortunately strained the relationships in my family. It has put a strain on my marriage to Dean, as some days I am very bright and bubbly, and other days I do not even want to get out of bed. I am not the same person that I was before my illness. I know that I am not the easiest person to live with at the best of times, but my illness put an additional, unnecessary and unfair burden on our marriage. This should not have happened when all we wanted was to have a baby.
47. My children have also found it very difficult to deal with my mood swings, anxiety and crying. They do not know how to respond to me because they

have not lived my illness. All of my children were grown up and living independently by the time I was diagnosed with hepatitis C. I think they were very shocked by the news that I had hepatitis. I have not really discussed with them how my illness has affected their lives, but I feel that I may have been too harsh with them. I know that for me personally, my infection has been the most traumatic experience of my life and I could not imagine anything worse. However, the ripple effect on those not infected but affected is equally important. I have spoken to the media on several occasions and been very public about my illness as I wanted to raise awareness about it, but perhaps I did not consider how this has affected my family.

48. Being part of Contaminated Whole Blood UK, firstly as a member and then as a leader, has been a huge part of my private life since becoming infected with hepatitis C. It gave me the support and motivation I needed to keep living my life. I have since told my story to the media and been involved with things like BBC's *Panorama* programme in the hope that I can help to raise awareness about the contaminated blood scandal and potentially save someone else's life, as there are likely still many people who do not know they have been infected with hepatitis C.
49. I was asked by the Hepatitis C Trust to be a peer patient reviewer and I was involved in the work of the ODN (Operational Delivery Network) as part of the medical inspectorate. I would describe their work as The Ofsted of hospitals. Each hospital and associated units in England were examined for their hepatitis C units. It was very difficult and draining for me, but I pushed myself to do it. I was left feeling mentally and physically exhausted.

Work-related effects of infection

50. Before I became too ill to work, I had loved working. My jobs gave me a sense of purpose. I worked at Marylebone Police Station as Civil Staff for

four years from 1983 until 1987. After that, I worked in the school, starting as a mum helper and then I supported children who had behavioural problems. This spanned over 10 years from 1992 until 2002. I then got a job as a receptionist at a law firm in 2004 and worked my way up to a personal assistant position. -

51. I left my job as a personal assistant when the law firm was shut down, and we moved to where we currently live. I then got a job at Tesco, even getting involved with running the in-house magazine for colleagues. I was one of four colleagues chosen to interview and report on the Christmas advert in 2015, which I was very proud of. However, I lost all of that with my illness. Tesco were very good to me and even kept me on their payroll for seven months after I was unable to work, but sadly this could not carry on indefinitely as they are a business and they need people to work. Therefore, I was medically retired in June 2016.
52. I felt like I lost my purpose when I was medically retired. I felt completely useless and a burden to my family. It was not that I was not working because I was lazy, it was because I could not physically work. I had previously been a very active person – I was a Brown Owl for seven years, school governor for 12 years and several years fund-raising for our school PTA. I coached a Colts cricket team for two years, coached, umpired and arranged kwik cricket tournaments between local schools for several years and was involved with coaching the school rounders team as well. However, I was forced to give up all of this because I was always extremely tired.
53. Dean stopped working in June 2016 so that he could look after me. I can get very dizzy and sometimes suffer from severe loss of balance, so I constantly require his assistance. I cannot do anything on my own without Dean now; I have lost my confidence to that effect. I cannot even take my grandchildren swimming anymore because I am not well enough and tire easily; just walking around a shop exhausts me.

Financial effects

54. Of course, the fact that neither Dean nor I can work has had an impact on our finances. As such, we have had to turn to the government for assistance. However, my experience with the Department of Work and Pensions has only added insult to injury. I feel like I have had to go to the government with a begging bowl, when it was through no fault of my own that I had to stop working in the first place.
55. I have had to explain to staff at the Department of Work and Pensions about the contaminated blood scandal and how I became infected with hepatitis C. I remember speaking to a member of staff on the phone and saying that I just wanted to know that the person I was being assessed by had an understanding of the contaminated blood scandal. I had to explain that I did not want to stop working, but that I had in fact worked with the illness for 28 years, getting more and more ill because of it.

Other related impacts of infection

56. I have never really felt stigmatised by my infection with hepatitis C, as I have always been more concerned about sharing my story and raising awareness of the contaminated blood scandal. However, I have still suffered from negative reactions from some individuals. I have received a death threat as a result of being so public about my infection.
57. It was early September 2018 when I received the death threat through Twitter. One Twitter user had sent me a photograph of a woman's neck being sliced, and captioned it "this is you". I was using my phone to browse at the time when I saw the pop up notification come up on screen. However, when I looked on Twitter again to trace the message, it had already been deleted. I was shocked, and felt very vulnerable for the first time in my life

because I was on my own. I have not had anything like that happen to me before or since that incident.

58. I have advised the Inquiry of this incident as I felt there ought to be a record in the event that something bad should happen to me.
59. Another event that had a very big impact on me was the commemoration event held by the Infected Blood Inquiry at the opening of the Preliminary Hearings. I was involved in the planning of the commemoration and knew exactly what was going to happen. Yet when I was sitting at the front watching the victims placing their messages in a bottle into a unit, watching their expressions of sadness, tears and grief has had a strong emotional impact on me.

Section 6. Treatment/Care/Support

60. I have never received any form of counselling or psychological support since being diagnosed with hepatitis C.
61. I have not experienced any difficulties in accessing treatment as a result of being infected with hepatitis C.

Section 7. Financial Assistance

62. I have received the stage 1 payment of £20,000 in May 2016 and the stage 2 payment of £50,000 in June 2016 from the Skipton Fund. I also receive ongoing monthly instalments of £1800 per month.

63. I was not informed of the Skipton Fund, but found out about it myself by chance when I was doing some research online about hepatitis C and medical negligence. I only thought about researching medical negligence as I had previously worked in the legal industry. Through researching online, I came across the Skipton Fund. I found the phone number, called them to ask for the application form, and gave it to my hospital to complete. However, my hospital was renowned for not filling out the forms out very quickly, so I called them again a couple of months later to ensure that the application form was completed.
64. The process of applying for financial assistance from the Skipton Fund was not straightforward. I had to be very pushy in gathering the necessary documents to prove I qualified for payments, and it was only through my diligence that my application eventually succeeded. It was difficult for me to obtain my medical records, because I was informed that they had been destroyed after 25 years. But then I remembered that I had the blood transfusion card and managed to find it.
65. My maternity records had been destroyed, but I called my GP surgery to ask if they had any documents at all that could explain my situation. The secretary then printed off a summary sheet which recorded the units of blood that I had received when giving birth to my eldest child and the twins. This fortunately meant that I could prove that it was more likely than not that I had been infected by a blood transfusion than by any other causes.
66. My other issue that I have with the Skipton Fund is that my payments were not backdated. The Skipton Fund has been in existence since 2004. However, I was not diagnosed with hepatitis C until 2015, despite raising concerns earlier to my doctors. I find it unjust that my payments were not backdated simply because I was diagnosed until much later, through no fault of my own.

Section 8. Other Issues

67. I have been involved in campaigning since I was diagnosed, I joined a couple of groups. The group Contaminated Whole Blood UK was then set up, and I was added to that group. One of the group administrators asked me to also become an administrator because the lady in charge, was very ill, she subsequently died. This administrator then left the group, effectively leaving me in charge. I could not walk away from the group, as it is the only group available for this specific type of infection. The term "whole bloods" refers to people who were infected by a blood transfusion, rather than a blood product. So I changed it to a support group rather than a campaign group. There are now 233 members.
68. I believe that the people responsible should be held accountable for their actions. Not enough has been done to help those who are already suffering through no fault of their own – why are infected people having to go to food banks because they cannot work and support themselves? It is not just the fact that you are ill, it is the injustice of the whole situation.
69. For me personally it is not about compensation; there is no amount of money that can give me back the future that I have lost and the years of my life that hepatitis C has stolen. I just want the people responsible to be held to account and if found guilty to be prosecuted.

Statement of Truth

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

Signed GRO-C _____

Dated 22/03/2019