Witness Name: Catherine Mahoney Statement No.: WITN5741001 Exhibits: WITN5741002-11 Dated: 2.6-11-2.1

# **INFECTED BLOOD INQUIRY**

# WRITTEN STATEMENT OF CATHERINE MAHONEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 May 2021.

I, Catherine Mahoney, will say as follows: -

# Section 1. Introduction

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- 1. My name is Catherine Mahoney. My date of birth is **GRO-C** 1954 and my address is known to the Inquiry. I live in **GRO-C** and I am a homemaker. I am married and I have 5 children and 13 grandchildren.
- 2. I intend to speak about my sister, Mary Rodgers, who we all called "Marie", and how she became infected with Hepatitis C (HCV). In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had her and the lives of her loved ones.
- 3. I can confirm that I am not legally represented and that I am aware of the anonymity provisions but I am happy for my statement to be in the public

domain. I am also aware that if I am critical of a medical professional then it is likely they will have a right of reply.

# Section 2. How Affected

- 4. Marie was born on **GRO-C** 1941 and was one of 6 children, 5 girls and 1 boy. My mother, who was also called Mary, told us that Marie was christened Mary by the nurse at the hospital who delivered her, as it had been a very traumatic birth and she wasn't sure that baby Marie would survive.
- 5. Back then, babies in that situation were christened with their mother's name in case they did not live. Although our priest told my mother she could change her christened name later on, she did not want to do this and instead at home we just referred to Mary as Marie, so there was no confusion.
- 6. My mother said Marie's birth was the only one where she had given birth in the hospital, and it was a terrible experience. She described being punched in the stomach by the nurse trying to get Marie to come out.
- 7. As far as I am aware, Marie had been disabled since birth and had always had difficulty with her speech and controlling her movements, often causing her to shake. However, Marie never received a diagnosis for her disability. I know that she saw Dr Gibson, a neurologist, who I believe was at the City Hospital, Belfast but he was not able to tell her what her disability was either.
- 8. GRO-C GRO-C GRO-C Marie, who struggled with her speech, asked the person testing us "what is wrong with me?", as she wanted to understand why she was the way she was.

- 9. The DNA doctor came in to see Marie and he said that he could see by just looking at her that she had been damaged at birth, and that was the cause of her disability rather than any genetic issues, and this lined up with what my mother had told us about Marie's traumatic entry to the world. I don't know who the doctor was but he worked at the Bridgewater Suite at the City Hospital.
- 10. Despite her disability, Marie was always fit and strong. She would be up for anything and always enjoyed going away and doing things with the family. We went on many foreign holidays together which she always enjoyed.
- 11. Everyone knew Marie where we lived, and people looked out for her. Sometimes people didn't understand her speech and would direct questions to me about her if we were together, but I would always tell them to talk to her and not to me. She was independent and had her own way of doing things.
- 12. Marie went to a normal school and did not receive any benefits or extra support while growing up. When she finished school, there was no work for her to go into, and she started receiving public assistance which was 17 shillings and 6 pence to live on.
- 13. When Marie was around 20 years old, she went to see Dr Fletcher, a heart specialist at City Hospital in Belfast. He said that Marie had rheumatic heart disease and that my mother should take her home and be good to her, as she wouldn't make it to her 21<sup>st</sup> birthday. I remember seeing tears dripping off my mother's face, even though she tried to stay strong for Marie and the rest of us.
- 14. Dr Fletcher never sent for Marie again, but she made it made it well past her 21<sup>st</sup> birthday. After this, the unemployment office felt there was surely some field Marie could work in, and I remember she went on a 6 week visit to Portadown, where they assessed whether she was capable of working. Following this assessment, Marie went to work at the workshop

for the blind where she painted straps on satchels. Despite her shakes, she managed to find a way to do this.

- 15. Marie worked at the workshop during her mid 20s, and despite it being during the middle of 'the troubles' and living near **GRO-C**, she said it was the best years of her life. She had the opportunity to meet other disabled people and she met her husband John there too. She would tell us stories about her time working there and how they would all take the mick out of each other.
- 16. Marie married John Rodgers in 1975. John was also disabled, and had severe scoliosis, sleep apnoea and required breathing tablets. He was 14 years older than Marie. He absolutely adored her and lived his life for her.
- 17. Not long after they got married, Marie suffered a miscarriage. When she visited City Hospital in relation to this, they became aware of her again and realised she had not died by 21 years old like Dr Fletcher thought she would. She was seen by Dr Morton, who felt that Marie might benefit from cardiac surgery.
- 18. In 1976, Marie had major surgery to replace a damaged heart valve and repair a mitral valve. This operation was performed by a surgeon called Dr Cleaning at the City Hospital (I'm not sure how his name is spelt). Marie spent 3 days in ICU and then 3 days in a high dependency unit before being moved to a ward. Although she felt well after the surgery, Dr Cleaning did not think it had been successful.
- 19. Sometime after Marie had recovered from the surgery, in around 1983 she started feeling tired and unwell. At an appointment Marie had with Dr Morton which my sister Eileen accompanied her to, he asked Marie how she was feeling and she said she was okay. Eileen knew she had been feeling tired, and poked her and told her to tell this to the doctor, which eventually she did.

- 20. Marie underwent further testing and it was found that she would require another surgery, which was done in 1983. I later learned from the nurse looking after Marie that she had to be revived twice on the operating table. Around 3 days after her surgery, I went to visit Marie. As I am 13 years younger than Marie and looked very young at the time, they allowed me to visit as they thought I was her daughter.
- 21. When I saw Marie after this surgery, her chest was black and blue, which was very different to the first operation. She also had various tubes going into her, and I saw that she was being transfused with something. Other than myself, only John was allowed to visit her at this time. However, John was always just concerned about making sure Marie was alright as he loved her so much, and did not really inquire about the details of her treatment or what had happened.
- 22. Around the time that Marie had these operations, she also suffered from a burst appendix and required an operation for this, but I cannot recall the exact dates of this. After undergoing all these operations, Marie did not go back to work but John continued to work for many more years. After John eventually stopped working as he was finding it difficult to cope with a job, they both relied on disability living allowance ("DLA")
- 23. Over the years Marie was monitored for her heart conditions, but generally she was quite well. She did suffer from tiredness and at times, lethargy but we always put this down to her heart condition and disability, and we never noticed a major decline in her energy levels. She had regular blood tests as she was on Warfarin, but they never picked up anything wrong.
- 24. Sometime in around the late 90s, Marie starting suffering from an upset tummy and she would regularly throw up after eating. All of Marie's siblings would look after her and do things for her, and Eileen noticed that Marie had thrown up her dinner that she had given to her. It was strange as Marie usually loved her food and did not have any digestive

issues, but we never connected it to anything. I just thought I should get her more fresh food.

- 25. I think at some point I also noticed that Marie's colour was a bit off, but we always put it down to issues with her heart. Our mum had been told Marie would die in her 20s, so we always thought any health issues Marie might have would be linked to that. It was only later that we realised that she had been going yellow with jaundice at this stage.
- 26. During this period when Marie was throwing up and feeling unwell, Eileen went with her to her GP which was the Clifton Street Surgery. They seemed to assume it was a gastro issue and she was prescribed cyclizine, an anti-sickness medication. I think they thought she was just generally unwell, and said to monitor her diet and things like that.
- 27. Saturday used to be the day I would visit Marie and I would do her hair for her, as I am a hairdresser by profession. I asked Marie if she was feeling okay. It was around this time she was having this period of sickness and she said that she had noticed that she was getting a bit skinny.
- 28. When Marie's health had not improved and she was still feeling unwell, Eileen took her back to her GP Surgery, and they ordered some blood tests for her. She was eventually referred to see Dr McVeigh at Belfast City Hospital in July 2001. At her first appointment with Dr McVeigh I believe he ordered more blood tests, and she was then invited to come and see him for a second appointment after these tests results came back. (See Exhibit WITN5741002)
- 29. Marie went to this second appointment with Dr McVeigh on her own using the bus. At this appointment, Dr McVeigh had told Marie she needed to go and see a doctor in the gastroenterology department, and walked her across the hospital to see Dr GRO-D. (See Exhibit WITN5741003)

- 30. Dr <u>GRO-D</u> told Marie that she had HCV, which is a disease of the liver. He told her that she needed a scan, and asked her to walk to the relevant hospital department to go and get one, and then come back and see him. Marie was on her own and obviously terrified and upset by this news.
- 31.1 was personally horrified by this revelation and the way Marie was treated left on her own and afraid. It was this and other incidents that led to my involvement and I determined to fight Marie's corner and ensure her voice was heard.
- 32. A nurse who knew Marie at the hospital saw that Marie was struggling to walk down the corridor to go and get her scan, as she was so nervous that her shakes were even worse than usual. She had put her arms around Marie and asked her what was wrong, and Marie told her about the HCV diagnosis. She told Marie not to worry because it is an infection that you can live with for years without any problem, and walked her to her scan. Marie was never given a result from this scan.
- 33.As far as I am aware, at this appointment Dr GRO-D gave Marie no information about HCV or any precautions that should be taken to avoid infecting others. She had not even known she was being tested for HCV prior to her diagnosis. There was never a suggestion that her husband John should be tested for HCV, nor any of the rest of the family and it was never something we thought about at the time.
- 34. When Marie was told about the HCV infection, she was told that she likely contracted it through a blood transfusion during her heart surgeries in 1976 and 1983, and this is what Dr McVeigh told Dr **GRO-D** too (**See Exhibit WITN5741003**). These were both major surgeries which would have required blood transfusions.
- 35. Marie was happily married, had never been an intravenous drug user, had no tattoos and had never received medical treatment abroad. There were no other risk factors in her life for HCV apart from blood

transfusions and as far as I am aware the transfusions during heart surgery are the only ones she has received.

# Section 3. Other Infections

36. I believe that Marie was told that she would be tested for HIV, but I don't think it was mentioned again, so I assume she tested negative for this. As far as I am aware, she was not infected with any other infections as a result of the blood transfusions she received.

# Section 4. Consent

- 37. I am not aware if Marie was asked to sign consent forms prior to her preplanned cardiac operations. As far as I am aware, she was not made aware of any potential risks associated with a blood transfusion during the operations, and was not even made aware prior to the operations that she would be given blood.
- 38. Marie was not made aware that she going to be tested for HCV, and was never asked to consent to this test.

#### Section 5. Impact

39. Marie was extremely upset and worried about the HCV diagnosis, and did not really understand what it meant. She thought she was going to die and it was devastating for her. We were all very upset too and it was awful news, but we reassured her she was not going to die and tried to find out as much as we could about HCV. To me, it felt like they had taken an already frail person and given her a death sentence.

40. GRO-C So we tried to reassure her about this and thought that some treatment would be made available for her going forward. Most of our information about HCV came from his

experience, and things we saw on television. There was little or nothing from the medical professionals.

- 41. Marie's husband John was always someone who tried to brush off issues and act like nothing was wrong. Even after Marie was diagnosed, he kept saying it would be nothing and she would be okay. Even when it came to his own health he never really took things seriously and would not take his medication properly. In effect, he buried his head in the sand. I think that is how he dealt with her diagnosis, as he loved her so much and could not think of her being unwell or face the prospect of losing her.
- 42. Dr **GRO-D** brought Marie in for another appointment which she attended with Eileen. As far as I am aware, Dr **GRO-D** told Marie that she was not fit for any HCV treatment due to her heart condition and poor health. In my opinion this was also linked to the fact that she was disabled. She was told there was nothing they could do for her.
- 43. Dr Smyth, Dr <u>GRO-D</u> 's registrar had written to Marie's GP around this time confirming she had tested positive for HCV but that her HCV PCR test was negative. I don't believe Marie really understood what this meant at the time as it was never explained to her. (See Exhibit WITN5741004)
- 44. We knew that GRO-C had lost a lot of weight on the Interferon treatment, and we believed that the doctors thought Marie was not strong enough to cope with treatment. However, despite being disabled, Marie was very fit and strong. One our aunts even said to Marie, "they thought you would be dead years ago, and you're still hers so you'll be okay".
- 45. As far as we were aware, the doctors were telling Marie that she had HCV but there was nothing that could be done to help her. It felt like it was more or less a death sentence for her and it would be a slow one. Marie would only have a doctor's appointment every 6 months or so for monitoring purposes, but these were always very quick and did not offer her any new treatment.

- 46. We tried to make the doctors aware that Marie was very fit and strong, but I do feel like they saw her disability first. We were made to feel that Marie just would not survive Interferon treatment, and we were left thinking that all we could do was give Marie the best life possible.
- 47. In 2001 when Marie was diagnosed, she was still very active and would enjoy going out with some girlfriends on Saturday. She enjoyed her life and had always had inner strength. As mentioned, she would always be up for anything.
- 48. After Marie was diagnosed with HCV, she was more worried and I noticed she would hang on my arm a bit more. She became more withdrawn. She used to do things like sponsorships for the school and would always want to go on a little holiday, but over the years she became more reclusive and did not leave the house as much as she once did. Eventually she stopped going out on her own at all.
- 49. In 2005 when Marie had received a refusal from the Skipton Fund, I was very confused by their reasons and wanted clarification in relation to this. I accompanied Marie to an appointment with Dr Ali. I asked him to explain to me why Marie had been told she had HCV, but was not eligible under the Skipton Fund criteria. I also asked to speak to Dr GRO-D, but he did not want to come and see me, and I believe this is related to the Skipton Fund application, which I will discuss later in my statement.
- 50. Dr Ali told me that Marie's blood tests showed an intermediate level of HCV. He said that the histology showed that Marie had definitely had an episode of HCV in the past. However, what the Skipton Fund wanted was a positive PCR test from Marie, which she did not have at the moment. (See Exhibit WITN5741005).
- 51. Dr Ali was nice and helpful, and I asked him so many questions, but he said that unfortunately he just could not get me what I needed. He did another PCR test on Marie at this time which was negative. Dr **GRO-D**

confirmed Marie's negative PCR results when writing to her GP Dr Maguire on 27 November 2006 in relation to a steroid injection for Marie. (See Exhibit WITN5741006)

- 52. As I felt like Marie was not being offered treatment that could potentially help her, I wanted to contact Dr Cleaning, the surgeon who had performed both Marie's heart operations. I know that he had performed these surgeries against the advice of other doctors, who did not think Marie would survive these procedures as she was disabled. He realised she was strong and I hoped that he could recommend that she was strong enough for HCV treatment too, but unfortunately, he had retired by then.
- 53. Over the years, Marie's health deteriorated and she became more and more reclusive. My sister Margaret cared for Marie and she had a home help going in. The weight was dropping off her and I used to think she look a bit greenish yellow sometimes, but I never wanted to tell her this as she was already by upset by it all. I remember her saying once, "they damaged me at birth and now they are damaging me again".
- 54. I have no idea what was being done at appointments Marie had over the years, but she was never really sent to the hospital and only attended the doctors if she was throwing up or unwell. Marie only really saw her GP during this period, and I don't think they were doing much to help her. It felt like there was nothing that could be done, and we just accepted it. In a way we felt like no news was good news in terms of her health.
- 55. Marie had not had a liver biopsy after she was diagnosed, as she was on Warfarin and Dr GRO-D ruled it out because of that. It would have confirmed the extent of Marie's liver damage, but I believe they already knew her liver was damaged from the scan Dr GRO-D sent her for when she was diagnosed.
- 56. I remember when doing her hair for her I asked her why she never looks at her hair once it's done, and she said she prefers to look at me instead

and that she tries to think of herself as me. I told her, "Marie, there is nothing wrong with you", but she said, "there is". It was sad to see her this way.

- 57. In 2009, Marie was just sitting in her living room when she coughed up some green bile onto her hankie. It was a Saturday and I was with her at the time, so I said I would take her to the Mater Hospital GRO-C
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  , but she wouldn't go, as she didn't like this hospital. The week prior to this incident, Marie had not been very well and I had been taking her bits of food round, like fruit. However, at the time we did not know how unwell she actually was.
- 58. Eileen took Marie to the Royal Hospital on the Monday as he had deteriorated and she was admitted to a ward. We knew she was unwell, but she had walked into hospital and we assumed she would be in hospital for a few days and be home again. However, this was not the case.
- 59. Marie was being treated by Dr **GRO-D**, and he spoke to my sister Margaret and explained that Marie was quite unwell but they were supporting her as best they could. Marie's liver was very swollen and scarred, which was putting pressure on her heart.
- 60. He told Margaret that they were giving Marie a drug to strengthen her heart and were waiting to see if she could come through this episode. This was clearly an episode of HCV, despite Marie being told she did not have chronic hepatitis. What else could have caused such damage to her liver?
- 61. I recall a cardiac surgeon visiting Marie around this time and he said that they would be able to fit her with a pacemaker, which could improve her heart condition. However, Dr **GRO-D** and other doctors observing Marie felt that she was too unwell by this stage to have any further interventions.

- 62. Marie was moved to the ICU and Dr <u>GRO-D</u> told us that her condition was deteriorating rapidly, and it was unlikely that she would make it out of the ICU. I explained to the nurses that Marie did not want to be left alone, so her siblings would be taking turns to sit with her and would not leave her. It was agreed as long as it was just one of us sitting with her at a time, that would be okay.
- 63. As we had been told by Dr <u>GRO-D</u> that we were looking at the last of her, we did expect Marie to die quite quickly and ensured there was always someone with her. However, this went on and on and she showed she had no intentions of dying without a fight. By this point she was pure yellow, and even the whites of her eyes were yellow. I still did Marie's hair while she was in hospital and looked after her as best I could. She knew she was dying and she was frightened and confused.
- 64. At the time, we trusted the doctors when they said there was nothing they could do for her. We just watched her condition get worse and worse, and her legs eventually started to swell significantly, something she had not experience until she had been in hospital for some time. It was effectively palliative care.
- 65. Marie ended up being in hospital for 10 weeks in total. Dr GRO-D told me that he wished he could go back in time 10 weeks and he would have done more for Marie, as he did not realise how strong she was when she was first admitted. He had thought she would die quite quickly but this clearly did not end up being the case and now she had deteriorated significantly while in hospital.
- 66. I asked Dr <u>GRO-D</u> why he was telling me this now, when it was too late to change anything. I reminded him that I had told him at the start that she was fit and well. He was a lovely man and I think he believed he was just going to prolong the inevitable by doing medical interventions on Marie. I wish he had provided me this information in writing, but I'm sure he would never have agreed to that.

- 67. Marie was still alert and eating her meals when she was in hospital, and we would play her the golden oldies music. She did not seem like someone dying and only really went downhill quickly after being admitted.
- 68. John, Marie's husband, seemed to be living in denial as Marie's condition deteriorated, and just could not seem to understand what was happening. He kept saying and thinking that she would be alright. Although John was Marie's next of kin, one of the siblings should have really played this role as he was struggling a great deal and was not really able to focus enough to make decisions about her care.
- 69. Dr **GRO-D** said that Marie could go home, as being in hospital was just keeping her alive without any quality of life. He basically said that we would end up killing her at home, as we would not be able to say no to her if she asked for more food and water and water was a problem because of fluid build-up. It was a strange remark to hear. She was brought home on a stretcher.
- 70. Marie came home with a catheter in but the tube that was draining fluid from her abdomen all the time she was in hospital had been removed.I do feel they had removed this as they had sent her home to speed up her death, and draining the fluid in her abdomen was probably keeping her alive.
- 71. All the family members looking after Marie were likely giving her water to drink, probably more than she was meant to have but we wanted her to be comfortable. The carers that helped us during this period were helpful and supportive. We also got a vibration bed for Marie to use at home during this time.
- 72. Around 10 days after Marie had come home on 13 June 2009, at about half past 6 in the evening, my brother's daughter Judith came over to spend time with Marie, and told me to go home and get some rest as I looked tired. Judith and Marie had a close bond, and Marie enjoyed her

company. At about twenty to nine in the evening, while they were having a conversation, Marie stopped replying and Judith realised that Marie had passed away.

- 73. God was good to her as she passed away peacefully and with family by her side. Marie had been scared about being on her own when she died and saying goodbye to us, and I told her I would pray that should would never have to say goodbye to any of us. As she passed away mid conservation, this prayer came to life and Marie never had to say the goodbyes she so dreaded. Marie had even asked for ribs to eat on the day she passed, so she was still eating and alert until the end.
- 74. Marie had felt that no one had ever taken responsibility for what was done to her, when she had done nothing wrong. She had always been such a strong person and despite her disabilities, she always managed to do things for herself and in her own way. She was able to laugh at herself and I remember she would cry with laughter when the kids used to mimic their aunty Marie. She was an integral part of the family and her death was absolutely devastating for her husband John and the rest of her family.
- 75. After Marie's death, I called Michael at O'Kane funeral directors, who were well known in the area. They told us to keep our Marie as long as we liked, and they ended up taking her away at 3am. I didn't know at the time but they had embalmed her not long afterwards, and they called me in the morning and asked me for a death certificate for Marie.
- 76. I had a few issues getting this death certificate, which would have been a problem for the funeral directors as they had already embalmed her and an autopsy could not have been performed after this was done. I think they had gone ahead and done this for us as they knew Marie, but technically speaking you need to have the death certificate first.
- 77.A locum doctor had come out after Marie had passed away to confirm her death and remove her catheter, but he had not left his name or any

of his details so we could not contact him in relation to the death certificate. We also called the hospital about the death certificate, but as Marie was not under their care at the time of her death, they were not willing to help with this.

- 78. In the end, I called Marie's GP on the Monday morning who also said they can't issue it. I spoke to someone who worked on the GP reception who had gone to school with my son, and I told him I was coming straight over to sort it out, as I was so angry that it was taking so long to deal with it. When I got there, I was told that the doctor was doing it for me.
- 79. On Marie's death certificate (See Exhibit WITN5741007) it listed Marie's cause of death as congestive cardiac failure, mitral valve disease and chronic hepatitis C. It provided even more proof of Marie's HCV diagnosis and that it was contributory and had an impact on her death. Her liver was cirrhotic according to the doctors and badly swollen, causing it to pressurise her heart. The women in my family are long livers and a lot of my aunts have lived well into their 90s, and I feel that Marie, despite her heart problems which she had coped with admirably, would have lived far longer if not for the HCV.
- 80. Marie's husband John's really struggled with his mental health after her death. He just could not understand how he was much older than Marie but she had died before him. She had died when she was just 67 years old, and he was 81 years old at the time.
- 81. John would not come out of his grief. I remember that he would tell people not to sit in the chair that Marie used to sit in as it was still Marie's chair, and kept her scarf on it. His purpose in life was looking after Marie and he just did not know what to do with himself once she was gone. With her shaking problem, he was always the one to make breakfast and dinner for them, so he had always been busy doing things for her. Everyone in the neighbour knew John and Marie as a couple, and they had a nice life together **(See Exhibit WITN5741008)**

- 82. As John's physical and mental health started to deteriorate after Marie's death, **GRO-D** stepped in as his next of kin and put him in a nursing home. If you knew John you would know this was the absolute worst thing for him. John died 2 years after Marie's death in 2011, at aged 83.
- 83. After Marie's death I felt guilty that I had not pushed hard enough for Marie to receive some treatment for the HCV, and I wondered if I had done so, whether she would still be alive. I wanted to hit the rewind button and change things for Marie. I felt like I had nothing under my control back then and we had been side-lined.
- 84. Although I had gone to see Marie's doctor over the Skipton Fund application, I wish I could have got more things in writing, including their decision not to offer her any treatment. My friend told me that I should have asked for their reasons for not offering her Interferon treatment in writing, but you realise a lot of things with the benefit of hindsight.
- 85.1 also wish I had in writing what Dr GRO-D said about wishing he could go back in time and treat Marie when she first came into hospital, as he didn't realise how strong she was. Maybe if she had been treated differently from the start, she would still be here today. I think I used to be too accepting of what doctors said, and just trusted they were acting in the patient's best interest.
- 86. Marie was a very good person and I would always tell her anything that was bothering me. She always reassured me when I was worried about something, and she was like a mum to me with our age difference. If we were stuck for money, she would always help us out.
- 87. Losing Marie felt like losing my mum again. She gave me so much, and I feel that people – those who didn't know her, always felt that she did not have much to offer as she was disabled, which was so far from the truth. I wanted her to live a much longer life, and I really do believe she could have done.

- 88. I remember a doctor once saying to Marie that she did so well despite her disabilities as she was born that way, and her body never knew anything else. She adapted and did things her way.
- 89. Thankfully, Marie did not suffer any stigma associated with HCV, as no one really knew what it meant or what the associated risks were while she was alive. She always had her family and John around her, which I am thankful for. Both Marie and John are buried in Carnmoney Cemetery and we still go and visit them.

#### Section 6. Treatment/Care/Support

- 90. As far as I was aware, Marie was never offered Interferon or any other treatment for HCV as the doctors treating her considered her too weak to cope with the side effects of the treatment. Marie was also not offered treatment towards the end of her life, which Dr **GRO-D** later told me he regretted. I believe she was often written off because people saw her disability first.
- 91. When Marie was in hospital for her operations and various treatments over the years, the nursing care she received was generally adequate, but I do recall a nurse saying to her 'don't your hands work?', when she struggled to cut up her meat due to her shakes, which was unkind.
- 92. Marie had all her teeth filled by the time she was diagnosed with HCV, so I don't think she had any subsequent dental treatment following her diagnosis. I certainly don't remember any issues in relation to this.
- 93. Marie had no proper psychological help or support offered to her. Her GP, Dr GRO-D, arranged a counselling session which he conducted himself but never referred her to any professional counselling service. Marie took this offer of counselling but only attended one session.

- 94. She later told me that all Dr **GRO-D** did was talk, and he clearly wasn't listening to anything she said. She told me that she had realised while she was talking he was staring out of the window and he took a good few minutes to respond to her after she'd stopped talking, as he was not concentrating at all. Marie had enough and swung her handbag over her shoulder and walked out. Maybe Dr **GRO-D** did not understand Marie's speech well, but he should have at least tried. She was far savvier than people assumed.
- 95. Marie had lived off state disability benefits from when she stopped working, and had never had problem with this. Being diagnosed with HCV did not affect this financial support she received.

# Section 7. Financial Assistance

96. Marie learned about the Skipton Fund through	GRO-C	
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June 2004, I took on the task of completing the application for Marie, and I submitted it to Marie's GP, Dr Martin Donnelley at the Clifton Street Surgery, to complete the form. I was told that the GP was away on holiday and would do it when he was back.

- 97.1 think Marie had been annoyed by the delay with regards to Dr Donnelley completing the form, and had been ranting to our sister Margaret, who was Marie's carer, about this. Margaret then filled in another Skipton application in August 2004 and took it to Marie's GP, and this time it went to Dr Maguire.
- 98.On the initial application, the GP had completed the form to say that Marie had HCV and was suitable for the Skipton Fund payments. However, due to the submission of the second application, Dr Maguire sought the assistance of Dr GRO-D in completing this form.

- 99. Dr **GRO-D** subsequently amended Marie's application to the Skipton Fund to say that there was no definite evidence of a chronic phase of raised liver function tests, liver histology or radiography or other symptoms suggestive of hepatitis C in Marie's case.
- 100. Dr <u>GRO-D</u> wrote to the Skipton Fund on 25 February 2005 said 'there is no definite evidence therefore of chronic hepatitis C infection and Mrs Rodgers is currently PCR negatively. I understand she will not be eligible for the ex gratia payment of £25,000'. (See Exhibit WITN5741009). When I later wanted to speak to Dr <u>GRO-D</u> about this, he refused to come and speak to, as I'm sure he knew I was furious about this. I felt like she had been refused by the fund as a result of his intervention.
- 101. Margaret feels very guilty for filling out this second application, and feels that she was responsible for Marie not getting the Skipton Fund payment. It still haunts her. That is part of the reason she did not come with me in order to give a statement to the Inquiry. However, she was only doing what she thought Marie wanted at the time.
- 102. After Marie's application was rejected by the Skipton Fund, I approached our MP Nigel Dodds in relation to this matter in early 2005. I explained to him what had happened and that there needs to be financial support made available to Marie who had obviously been infected by the NHS when her health was already compromised by her disability. The only reason why she was not getting this support was because she had no positive PCR test.
- 103. Nigel had a young disabled daughter who had died, and he was sympathetic to Marie's situation. He told Marie that he understood where she was coming from and said he would write to the Skipton Fund and the Department of Health if necessary.
- 104. Nigel took the matter to the floor of the House of Commons and also spoke to MP Douglas Hurd who was involved with the Fund, and

although he would not intervene, he said that if we explained our situation to the Fund, we should be able to get financial support for Marie. This gave me the impression that the Fund was discretionary.

- 105. On 25 April 2005, Nigel wrote to the Skipton Fund on Marie's behalf. He noted under the guideline 3C of the Skipton Fund, it states that people that have cleared the virus spontaneously after a period of chronic infection will be eligible for payments from the scheme, and that this was Marie's position.
- 106. However, Keith Foster of the Skipton Fund replied to this letter and said that Marie fell out of the schemes parameters as she cleared the virus spontaneously in the acute phase of the disease, which was confirmed by Dr **GRO-D**. He said that he can only administer the scheme as outlined by the Department of Health and has no discretion to waiver these medical parameters.
- 107. Nigel responded to this letter from the Skipton Fund on 3 May 2005. He said that having read the Skipton Fund guidelines they had enclosed, they had highlighted 3(g) but in 3(c) of the guidelines it states that people who have cleared the virus spontaneously after a period of chronic infection will also be eligible for payments from the scheme, so it is clear that those infected who clear the virus spontaneously may, in certain circumstances be eligible for a payment, which was the thrust of Marie's case.
- 108. Keith Foster of the Skipton Fund responded to this letter on 5 May 2005 and said that Marie's medication information confirmed by her consultant Dr <u>GRO-D</u> indicates she cleared the virus spontaneously in the acute phase of the disease and therefore, falls outside of the scheme's parameters.
- 109. Although Nigel had tried to help us, he was unsuccessful. It was very disappointing for Marie to hear this. It was never really about the money for her, but she felt that since she had been given this infection,

she should get something as an acknowledgement of what they did to her, as the infection still could have damaged her liver and caused her heath complications.

- 110. It felt to me as if the Skipton Fund were avoiding payment based on a technicality. However, more recently my daughter has explained to me that they were probably unable to give funds to anyone outside the criteria they were given, and the real fault lies with those who set up these narrow parameters, as they clearly did not want everyone to get the support.
- 111. Marie was a big charity giver, and did not think you should sit down for your Christmas dinner until you had given £1000 to others. She would have definitely given a large portion of the Skipton Fund money to charity.
- 112. In addition, as the hospital was unwilling to offer Marie the Interferon treatment, I was hoping we could treat Marie privately if she got this money. At the time I felt they were not offering Marie treatment as they thought she weak, and I thought if she did well on the treatment privately, the doctors would change their minds about treating her. I feel it may have presented another opportunity to prolong her life if it had been a successful application.
- 113. What upset me the most about this rejection was I felt it was linked to the discrimination Marie had often suffered in life due to her disability.

GRO-C	
GRO-C	but Marie was treated
completely differently	

completely differently.

114. Towards the last days of Marie's life when I was sitting with her, I said 'Skipton Fund' to her, i.e. what should we do? She told me to go ahead and take the money if we could get it. I then asked her whether it may be better if we let it lie now, and she said no. She wanted me to fight for her - even after she had gone.

- 115. After Marie's death I made another application to the Skipton Fund in April 2009. This time I had a copy of Marie's death certificate which listed a cause of her death as 'chronic hepatitis C' (See Exhibit WITN5741007). However, the Skipton Fund again rejected this application because there was no proof while Marie was living that she was infected with HCV beyond the acute phase.
- 116. They also said they not received copies of the medical records to confirm that Marie was treated with NHS blood or blood products prior to September 1991, which had never been in issue before. We tried to apply for Marie's medical records some time ago, but had been told they had been destroyed in a fire. I have tried recently again to apply for Marie's records, but I was told I would need to go to court and become Marie's power of attorney, and I wouldn't know where to start with it.
- 117. I went to see Dr Maguire, Marie's GP, who wrote to the Fund in December 2011 to confirm Marie's cardiac surgeries in 1976 and 1983, where she almost certainly received blood transfusions, as well as the lack of any other risk factors for HCV in Marie's life. (See Exhibit WITN5741010). Dr GRO-D also did a review of Marie's medical notes on my request, in relation to her HCV diagnosis. (See Exhibit WITN5741011).
- 118. In May 2012, the Skipton Fund Appeal Panel rejected my appeal using the same reasoning that Marie did not have a positive PCR test while she was alive, which was the test for chronic infection. By this point Marie's husband John had passed away, and I have kind of given up on the whole thing. While John was still alive I thought it would be nice to get something for him, but after this and his death it seemed pointless to pursue it.
- 119. Money from the Fund would never make up for taking Marie's life, but it would be an acknowledgment of what they did to her by giving her HCV. Towards the end of her life she was definitely having an HCV

related episode and had a swollen liver and jaundice too, but I just didn't think to ask them to do a PCR test at that point. However, the doctor signing off the death certificate was sure enough to include it as a cause of her death.

- 120. I feel angry and it devastates me that Marie never got anything from the Skipton Fund. Maybe I should have asked for help with the applications, but it was something private to Marie and it was something the two of us worked on together. I tried to sort it all for her, but it just didn't happen in the end.
- 121. None of the doctors have ever said that Marie's HCV did not damage her liver and contribute to her death, so the Skipton Fund criteria was extremely unfair in Marie's case. Blood test results can change within a few months, and maybe if Marie was tested earlier or later in her life she would have had a positive PCR test. In any case how long was she infected for before the test showed negative. It could have been years and all that time the disease is working against her liver. How else did she develop the liver problems the swelling, that led to her death?
- 122. I believe that being infected with HCV should be sufficient in order to access financial assistance. I don't just blame the Skipton Fund as they didn't set the criteria. Whoever agreed this criterion clearly wanted some people who had been infected to fail, which is very wrong. I believe the Fund was set up as damage limitation, not because they actually wanted to help people, as they would not have wanted anyone infected to miss out on financial assistance if their goal was to support people.

# Section 8. Other Issues

123. In around 2007, I was offered some blood tests following a pain in my shoulder. These showed raised LFTs, and I had a liver biopsy which showed a blockage in my liver. The doctors didn't know what is wrong with me and still don't. Initially they said it was nothing serious, but it has become worse and worse over the years.

- 124. As I received a blood transfusion in October 1981 at the Royal Belfast Hospital following a placental haemorrhage, I was really worried that I had also become infected with HCV. When I was tested for HCV, I was told my PCR test was negligible, not negative. I asked what that meant and I was told they could not say it was negative, as I had received blood in the past. I also cannot donate blood.
- 125. In 2009, I had a scan and it showed that my gall bladder had failed, but I was never given a reason as to why this happened. The radiographer also told me that my liver was full of stones. I have since had a procedure to remove these stones, although still, no one has told why this is happening.
- 126. In 2016, my liver started to fail and I had a liver scan. I have also had consistently high LFTs. I have seen a number of doctors in relation to this, including the top liver consultant **GRO-D**, who is the only doctor I really haven't liked.
- 127. My recent procedures have been done by Dr Kelly, a gastroenterologist at the Mater Hospital and he is brilliant. He always told me not to worry, although he said he couldn't diagnose me properly as I was a zebra, and they only know how to treat horses! However, in February he called me and told me he was worried about me, despite my levels being lower than they previously were.
- 128. I don't know if I have ever had HCV, but certain things like the fact that the doctors and nurses always double glove when treating me, does make me wonder about it. I have also suffered from bouts of jaundice, although at the time I thought I just had a tan!
- 129. When I have been getting insurance and I tell them about the liver stones and other symptoms, they always tell me that these are

symptoms rather than an illness or medical condition, but I have never been diagnosed with one.

- 130. I do feel those who are responsible for the use of infected blood know they did it, and should take responsibility. Why not tell people who received blood over the years to be careful, get tested and watch out for any symptoms?
- 131. I had my daughter after I was given blood and have always worried I could have passed something onto her, but I never mentioned it to her as I don't want to put the thought in her head. Even people who might not have been infected but received blood during those years have to live with the worry, although now all my kids are married and settled I'm a bit less worried about the future.
- 132. I do believe that Marie would have wanted me to tell her story, and even if nothing comes of it, that is okay. I just want to share what happened to Marie and the fact that she was still infected with HCV and suffered liver damage, which almost certainly hastened her passing. Even so, she was still ineligible for Skipton Fund assistance. In my opinion, with regards to Marie's HCV, "if it looks like a duck, walks like a duck and quacks like a duck, it is probably a duck", but not having a positive PCR test affected everything.
- 133. We pay a huge amount of tax, and I would want our money to be used to help people like Marie who were infected through no fault of their own. Marie was often dismissed and overlooked as she was disabled, and she would have wanted me to share her story and fight on for her to let her voice be heard.

# Statement of Truth

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

GRO-C Signed Dated <u>26</u> 21 [11]