

Witness Name: Margaret McIlwrath

Statement No: WITN1382001

Exhibits:WITN1382002-06

Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARGARET MCILWRATH

I, Margaret McIlwrath will say as follows:-

Section 1: Introduction

1. My name is Margaret McIlwrath, my date of birth is **GRO-C** 1950. I live at **GRO-C** Northern Ireland, **GRO-C** I live here with my husband John Maine McIlwrath. I have a son named Conan James McIlwrath, who was born on the **GRO-C** 1982. Conan and has severe Haemophilia A.

Section 2: How infected

2. I suffer from haemophilia A, which was originally classed as mild.
3. I received factor VIII blood products to treat me before and after a tonsillectomy I had in April 1980. My medical records show that I was given Kryobulin Factor VIII which I believe was an American product, manufactured by Immuno Vienna.

4. I was under the care of a Dr Elizabeth Mayne at the Royal Victoria Hospital, Belfast. When Dr Mayne was away, I was treated by a Dr Nelson, whose job was to administer the Factor VIII.
5. I believe I was given infected blood products between 21.4.1980 and 28.4.1980.
6. Because I suffered from haemophilia, Dr Mayne decided that my tonsillectomy should be done at the Royal Victoria Hospital in Belfast, where I could be treated with Factor VIII before and after the procedure. I was admitted and was treated with Factor VIII twice a day for several days prior to my operation, to prepare me for the procedure. Following the tonsillectomy, I bled so much that I required a blood transfusion, and was kept in hospital for longer than normal.
7. A few days before I was released, I started to feel unwell. I believe Dr Mayne was in London and three other doctors who were involved with my treatment came to see me on my release day. I was feeling very ill and I remember one of them saying "maybe she's got...", at which point he wrote something on a piece of paper or his hand and showed it to his colleagues. The one who appeared to be in charge said "It's just the junk we have been pumping into her. She is fit to go home." I later thought that the doctor who had suggested what I may have might have noticed a particular symptom in me, such as my yellow eyes.
8. After I was released, my health deteriorated very quickly. Around a week after I was released, my skin turned yellow and my GP came to my house and diagnosed jaundice. I could not the climb the stairs and could hardly move. I also had nausea and vomiting. It was the most unwell I have been in my life. These symptoms lasted for about a month, but it took 6 months before I started to feel back to normal.
9. A district nurse used to come out and take my blood once a week. One day my blood squirted out and gushed on to the floor, the nurse ran across the

other side of the room. I believe that they had knowledge of my infection then.

10. I believe I may have also received Factor VIII later when I had a tooth extraction and when I delivered my son via Caesarean Section in 1982. However, I am sure that I contracted Hepatitis C in 1980 from either the blood transfusion or the Factor VIII I received for my tonsillectomy, due to the period of very poor health I had after this.

11. At the time of my tonsillectomy, the doctor conducting the procedure asked me if I was sure about the operation. He said "do you know the risks... you're going to have Factor VIII" This did not sink in or trigger any concerns for me, because all haemophiliacs were having Factor VIII at that time. It was only later in life that I considered this to be a worrying comment. He didn't explain what the risks of being exposed to infection were from having Factor VIII.

12. As a result of being given blood products I was infected with Hepatitis C.

13. In around 1984, I noticed in the local newspaper that a new fatal disease was affecting homosexuals, Haitians, heroin addicts and haemophiliacs. I always remembered the 4 h's. It was a mystery disease. I went along to my GP to ask for a blood test for this disease. He was very dismissive of me, and actually laughed and told me that I was being paranoid. He tested me anyway and sent it off to the local laboratory. The following week I received a phone call asking me to attend the Royal Victoria Hospital in Belfast to see Dr Mayne.

14. I duly attended the hospital and Dr Mayne told me that she would need to do a blood test and that I may have AIDS, but it was very unlikely. It took around 6 weeks for the test result to come back. I spent the 6 weeks worrying myself silly. The test results finally came back negative and I was very relieved.

15. Shortly after this, reports started to emerge in the papers about a new strain of Hepatitis, formerly known as Hepatitis non-specific but they were now using the name Hepatitis C. The papers were saying that it affected, amongst others, haemophiliacs. Therefore, I attended my GP again and requested a

blood test for Hepatitis C. My GP laughed at me again, but did the blood test anyway. This time the result was positive.

16. I was informed that I had tested positive for Hepatitis C by Dr Mayne in 1992. I attach at exhibit "WITN1382002" an extract from my medical records of my test results from December 1992 for a number of potential infections. I also exhibit at "WITN1382003" a letter to my GP from Dr Mayne dated 21 December 1992 confirming that I had tested positive for Hepatitis C.

17. Had I not asked to be tested, I do not believe that I would have found out about my infection. None of the medical staff had told me and I had to find out for myself. I think that the medical staff should have been proactive in testing me for infections, as soon as it was known that I could have received infected blood products.

18. I was told by Dr Mayne that despite my Hepatitis C, I would probably have a long and normal life and that it was just a risk of having Factor VIII. Dr Mayne did not discuss any of the potential health issues; she just brushed over it very quickly. She did not discuss any treatment, although there wasn't any available then, or provide any advice on how to manage and understand the infection. She simply told me that I had it and it would do me no harm.

19. I therefore lived with the condition until I saw reports of haemophiliacs starting to die, not only from AIDS, but Hepatitis C. It was only after conducting my own research that I realised that Hepatitis C could do more harm than Hepatitis A or B.

20. I do not believe that I was provided with adequate information about my infection and most of the information I have discovered has been down to my own research.

21. I don't think I was given full information about the risks involved of receiving Factor VIII.

22. I was not given any information about the risks of others being infected as a result of my infection.

Section 3: Other Infections

23. I have previously received a letter stating that I was at risk of vCJD. I exhibit this letter dated 20.09.04 at "WITN1382004". When I received this letter I rang the hospital and asked them what this meant, I was informed that this was a standard letter that all haemophiliacs had received and told not to worry about it. Unfortunately, I did not keep that letter. Since then, I have seen a letter in my medical records sending me back into the community despite being at risk of vCJD.

24. Further to this, I believe I may have been exposed to Hepatitis G. At one point in the late 90's/early 00's, I saw a liver specialist who asked me to sign a consent form for blood tests. When I asked what they were for, he told me that it was to allow an investigation into Hepatitis G.

25. The next time I attended the hospital I asked a different Consultant about the Hepatitis G investigation and he searched for any relevant information, but he couldn't find any. My blood must have been tested for Hepatitis G, but I did not receive the results of this test. Neither did I receive any further information regarding this.

26. I cannot help but worry about the future. It is very daunting worrying what the next infection that we hear about could be.

Section 4: Consent

27. I do not believe I was treated without my knowledge or consent.

28. From reading others experiences, I do question whether I was used for research. I was what some termed a "virgin", a 30 year old haemophiliac who had never been treated with Factor VIII. I do not like to think of myself in that way and although I had great respect for Dr Mayne, this may be the case.

29. My initial thoughts were that imported Factor VIII was the only treatment available at that time, but as the years go on and the scandal emerges, I do question whether I was used for research.

Section 5: Impact

30. Since being infected with Hepatitis C, I have suffered from extreme tiredness. I used to think I was being lazy, but looking back I realise that it must have been lethargy I was from having due to the Hepatitis C. I found it very difficult raising a child with Haemophilia whilst suffering with Hepatitis C. The 1980's in particular were a very tough time for me, as Conan was born in 1982 and I believe I contracted Hepatitis C a couple of years prior to this.

31. I also suffer from a lot of stomach and gastric problems, which have slowly got worse as I've got older. I question whether these are related to my Hepatitis C. I have seen a gastroenterologist and had extensive investigations for my stomach problems of bloating, wind and continuous heartburn/indigestion, including an endoscopy. My doctors haven't commented on any link between my stomach problems and my Hepatitis C.

32. I suffer from depression and was prescribed Temazepam in the 1980s. I sometimes take one to sleep at night. I was also offered anti-depressants, but I threw these away. Although I did not worry about my infection when I was first diagnosed, I soon started to read about people dying from Hepatitis C and it placed a lot of strain on me. The trauma of the illness and the hard work bringing up a child with severe Haemophilia has left me exhausted.

33. I exhibit at "WITN1382005" a letter to the Legal Support Project in Belfast from Dr Gary Benson, my Haemophilia Centre Director dated 1 March 2016, which describes my symptoms and the interaction of my haemophilia and Hepatitis C.

34. Over the years, my Haematologist, Dr Gary Benson, has offered me an array of treatment to help 'clear' my Hepatitis C virus. I have always shied away from treatment, probably having a silly mind set that if I tampered with the

virus, it may just turn nasty towards me. I suppose I have lived with the infection in my body for so long, it has become part of who I am. After avoiding treatment for many years, I was told that I would eventually need it, so I took a course of treatment this year and I am awaiting the results. I now feel more unwell than I did before I started the treatment and wish I hadn't agreed to have it.

35. It has only been 6 weeks since I stopped the treatment, but I am still not feeling back to normal. I underwent a 3-month course of treatment, which started in around June/July 2018. Since then, I have felt very dizzy and have suffered from a dull headache, which I think may be related to having had the treatment. My energy levels have also been much lower and my stomach problems have also worsened since undergoing the treatment.

36. I know another haemophiliac who was treated with Interferon. They told me they felt "wonderful" after the treatment. I certainly don't.

37. As to whether my infected status has impacted upon my medical or dental treatment, I was released from the Belfast Dental Hospital due to being at risk of potential CJD or vCJD.

38. Having low energy levels has impacted on the things I can do with my family and friends. I often feel very excited for days or evenings out, but when the time comes, I sometimes cancel my plans, because I just feel too tired and I don't wish to do anything. This is becoming a more regular occurrence.

39. I have to be careful about my personal hygiene, so as to not risk infecting others.

40. When I discovered I was Hepatitis C positive, I told very few people. My husband knew, but I saw the impact the AIDS epidemic was having on the population and the stigma attached to these infections, so I kept quiet about my Hepatitis C. I told my dentist, who was very sympathetic and treated me no differently. He had the philosophy that he knew about my Hepatitis C

status, but he didn't know about everyone in his surgery who perhaps didn't even know what disease they were carrying. He treated everyone as if they were infected and took precautions. He was a lovely man and I respected him highly.

41. I had a terrible experience of the stigma associated with Hepatitis C when I was treated at the Royal School of Dentistry in Belfast. I developed a very serious abscess in the late 80's/early 90's and I was admitted to the School of Dentistry for treatment. I received intravenous antibiotics for several days, then on a Friday afternoon I was sent to theatre to have my tooth extracted.
42. When I was wheeled into theatre, two dental nurses came forward. One of them grabbed my left arm and looked at it. She said to her colleague "look, is that a needle stick mark?", whilst looking at the mark from my blood test. They were very abrasive and I could not understand why. I was given anaesthetic and when I came round I was still lying in the theatre. The nurses were cleaning down all of the equipment. "This is all for you", one of them gruffly said. It was only later that it dawned on me that they probably knew of my Hepatitis C status and thought that I was a drug addict.
43. I have always been careful in my dealings with others, knowing that some people might not be as understanding as others.
44. Financially, things have been difficult. I raised a son with severe Haemophilia A and I was carrying the virus for 2 years before he was born. I could not work full-time when he was young and found part-time jobs which meant I could work around childcare. However, as the infection started to affect my energy levels I found I wasn't able to work as much, as I required far more sleep than I normally needed.
45. I worked as a nursery nurse in the 1980's, then as a museum curator and then I worked in accounts for one of the big stores nearby.

46. Although I worked until I retired when I was 62, I was working very few hours a week. I worked around 4 hours per week, which is far from the 20 hours I worked part-time in a pharmacy when I was younger. I would have preferred to work full-time if I had the energy to do so, but my Hepatitis C has prevented this.

47. I applied for Disability Living Allowance on three separate occasions, but was always turned down, which made me very angry. The Government gave me my infection, but would not care for me. I think the fact that I looked normal was enough for the powers that be to always reject my claims. An ignorance about the disease also prevailed.

48. My infection has also has a significant impact on those around me. I think I have passed on a lot of my stress to my husband.

49. We were married for 8 years prior to my infection and we spent these years going on holidays and enjoying life. Then it felt as though we were plunged into madness, with my Hepatitis C and Conan being born with Haemophilia.

As a result of the worry, stigma and fear,

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50.

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51. With regards to my parents, I do not think they realised the extent of my infection. I know that my son, also a Haemophiliac who also contracted Hepatitis C, has been concerned about my health and he has provided a statement to this effect.

Section 6: Treatment/Care/Support

52. I can say nothing but good things about Dr Gary Benson, who now is the Director of Haemophilia at the Belfast City hospital. His care has been second to none. He has badgered me about going on treatment for my Hepatitis C, and I have always refused. I have finally given in and have taken the treatment.

53. I know that counselling is available, but at the present time, I don't wish to have any.

54. Patricia McGrath, the social worker attached to the Haematology unit at Belfast City Hospital put me in touch with a counsellor in 2016. Whilst I was there, I discussed my infection with the counsellor. I am still in contact with Patricia and when I informed her that I was meeting a Solicitor to discuss my witness statement for the Infected blood Inquiry, she said that if I need to talk, all I needed to do was to pick up the phone and she would arrange counselling for me.

Section 7: Financial Assistance

55. I received a payment of £20,000 from the Government many years ago, which has long gone.

56. I was refused the Skipton stage 2 payment. I exhibit at "WITN1382006" a letter from the Northern Ireland Haemophilia and Thrombosis Comprehensive Care unit dated 20.10.05 relating to this.

57. I now receive a monthly allowance of £480 from BSO/Caxton, which I have been receiving for over a year. I hadn't received any regular payments prior to that.

58. I have also had a couple of Skipton grants for things to make life a little easier. These grants have been used for a new fridge and a new mattress.

59. I hate going with a begging bowl every time something breaks down or needs to be fixed.
60. I have noticed that lately, a couple of requests I made were turned down. I do not think I ask for much, perhaps one item each year, but I feel like the proverbial leech every time. There have been things we have needed over the years and have not applied for.
61. My husband was seriously ill recently for several months and when he came out of hospital he needed extensive care. I am now his carer, but receive no help for this, because I am receiving my pension. I applied for a holiday, just to get some respite, but was made to jump through so many hoops by Caxton, I gave up on the request.
62. Times have been hard, given that I do not receive benefits and my Hepatitis C puts restrictions on my ability to work.
63. My husband worked until he was 56, but then GRO-C also prevented him from working.
64. I do not like the process of applying for financial assistance from Caxton. They seem to put more and more obstacles in our way, and require receipts for all of your outgoings. They have previously asked for receipts for everything including taxis, food etc.
65. In order to apply for a grant, you have to write or call Caxton and they will then send you a form. You have to send them 3 months worth of your bank statements and 3 quotes for whatever you want. If your request is permitted you have to send the receipt for the item you buy. When giving a grant, Caxton will always give you money for the cheapest quote you have provided. It is humiliating to ask.
66. The trusts and funds are useless, as they keep changing the goalposts. They have tried to string this out for so long and I think this is so that more people will die before anything really happens. This has added to my stress over the

years, as it feels as though you meet a brick wall everywhere you turn. A more generous scheme would have relieved my stress and made things more comfortable for my family and I.

67. I feel that the groups set up by the Government to offer financial help are an absolute joke. Why should I have to go cap in hand to ask for help when I have been put into this position by others? I was refused DLA by an uncaring system. Now I have to share my personal and financial life with strangers when I ask for something like a new washing machine, which due to my incapacity to work I cannot afford to buy myself. This whole affair stinks to high heaven.

Section 8: Other Issues

68. In addition to struggling financially, I have been unable to get life insurance due to my Hepatitis C status.

69. As well as being infected with Hepatitis C myself, I have been affected by my son contracting Hepatitis C due to receiving contaminated blood products.

70. Conan suffered his first bleed when he was 6 weeks old, and since then he received Cryoprecipitate and Factor VIII treatment for his Haemophilia. I am not sure how much Factor VIII he received, but I know that he received it in the early 1980s. He received treatment with blood products around twice a week, but when he had a bleed he would attend hospital more regularly. In particular, I remember he had an ankle bleed that required treatment at the hospital every day for 3 months.

71. There may have been times at the beginning, during his first or second year of treatment, when Conan did not receive Scottish products. When he was around 6 years old, I remember he was treated at hospital in Stevenage when we were on holiday visiting my sister in London.

72. Around this time, I was aware that the treatment for Haemophilia was changing. In around 1983/4, they were trying out heat-treated products and

when they didn't use these, they were trying to use Scottish products on children to make it was as pure as possible. This was at the start of the AIDS epidemic, so it made sense that there could be implications of using blood that was not pure.

73. I do not remember when we were told that Conan had contracted Hepatitis C, but I remember he was about 2 or 3 years old. I do not recall being given any much information about what this meant for him.

74. As a mother I was already concerned about Conan's Haemophilia, but we were told that all haemophiliacs had Hepatitis C and that we should not be concerned, because Conan would still live a long and happy life.

75. At this time I was still not aware of the risks of Hepatitis C or how to manage the infection. I do not recall Conan ever being specifically tested for any other infections, but I know they took a range of blood tests every 6 months or so.

76. I am not sure whether Conan was treated or tested without my knowledge and consent, but I know that he was a tiny baby, so all we could do was put our trust in the medical professionals to take care of him.

77. The thought that the doctors could have performed testing behind our backs is obnoxious, but it could have happened.

78. When Conan was around 6/7 years old, Dr Elizabeth Mayne told me that she had great news and that Conan had cleared the virus. When I told Dr Dempsey about this he was furious and said "that is absolute nonsense. You do not clear it, nobody does... it just hides!"

79. It seems unfair that someone should have to cope with Hepatitis C, when they already have haemophilia. Although Conan's Hepatitis C is no longer detectable, we are aware that it will never be completely cleared and he still has regular blood tests to check his Hepatitis C. In the last 7-9 years these tests have reduced to once or twice a year, instead of one ever 4 months.

80. Further to this, my uncle had Haemophilia and received Factor VIII. This was before they had made the connection with HIV and blood products. The doctors said that he died of a stomach blockage, but I believe that he died from AIDS.

81. I am now 68 and wonder if I will see an end to this whole affair.

82. I wish to apply for anonymity. I would be willing to give oral evidence to the Public Inquiry.

Statement of Truth

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

Signed. GRO-C

Dated... 14 - 12 - 18

CHRONOLOGY OF MEDICAL RECORDS

Treatment record

22.04.80 2 x KB (Kryobulin) Batch: 09M06179
22.04.80 2 x KB (Kryobulin) Batch: 09M06179
22.04.80 2 x KB (Kryobulin) Batch: 09M06179
23.04.80 2 x KB (Kryobulin) Batch: 09M06179
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25.04.80 2 x KB (Kryobulin) Batch: 09M06179
26.04.80 2 x KB (Kryobulin) Batch: 09M06179
27.04.80 2 x KB (Kryobulin) Batch: 09M06179

Virology results

05.09.83 HBsAg negative in serum.
14.05.86 Anti HTLV Negative in serum.
04.12.92 Anti Hep C virus – positive. Anti HIV 1 and 2 negative/HBsAg negative/
Anti HBs negative/Anti HAV IgG negative.
04.07.95 Hep C virus RNA positive/Hep C virus genotype 1b identified. .
01.12.98 Hep C virus RNA positive.
01.12.98 Hep C virus genotype 1b.
24.03.00 Hep C virus PCR positive.
27.03.00 Hep C virus PCR positive.
30.05.01 Hep C virus antibody reactive.
15.06.01 HCV PCR positive.
04.12.01 Hep C virus antibody reactive.
14.12.01 HCV PCR positive.
13.09.03 Hep C PCR positive.

Relevant correspondence

- 24.07.85 Letter from the Royal Victoria Hospital, Belfast inviting patient for testing for the AIDS virus.
- 21.12.92 Letter to GP, Dr Howie from Dr Mayne, Consultant Haematologist "I can now let you know that Anne (Margaret) is HCV positive. She is Hepatitis B Negative and has no other virological complication of past treatment. You will recall that Anne became jaundiced after her tonsillectomy in 1980. At that time Factor VIII blood products had not undergone heat treatment. This was instituted in 1985. Therefore it was very likely that she would have received infection with Hepatitis C."
- 20.09.04 Letter to client informing her that she is at risk of vCJD.
- 29.02.08 "Due to receiving previous plasma, she is Hepatitis C positive and would be viewed as a public health risk as regards to vCJD, although this planned surgery does not pose any risk". Letter to Professor Spence, Consultant Surgeon, Belfast City Hospital from Dr Gary Benson, Haemophilia Centre Director.
- 13.03.17 "In the dental hospital it was judged that she was at risk of potential CJD or variant CJD. Upon discussing the case with Dr Brian Mullally, we felt this patient would be best served with Community Dental Service".
- 20.09.17 "The results are in keeping with the presence of significant hepatic fibrosis, but fall short of our cut off for liver cirrhosis. I have counselled Mrs McIlwrath about today's results. She has been added to the waiting list for Hepatitis C treatment. Letter to GP from Dr McCorry re fibroscan on 14.09.17

Relevant clinic consultation entries

21.04.1980 Admitted for tonsillectomy.

28.04.1980 Discharged following tonsillectomy.

03.10.06 Not anxious for combination therapy. Bit concerned re condition of liver. Has bloating of abdomen (previously investigated by gastroenterologist).

29.05.07 Generally well, still some bloating (...illegible).