

Witness Name: Carolyn
McGimpsey
Statement No.: WITN3477001
Exhibit: WITN3477002-015
Dated: 30th June 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CAROLYN MCGIMPSEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 27th June 2019.

I, Carolyn McGimpsey, will say as follows: -

Section 1. Introduction

1. My name is Carolyn McGimpsey. My date of birth is the GRO-C 1959 and my address is known to the Inquiry. I am married to my husband of thirty seven years Robert McGimpsey. We have two boys, Craig who is thirty years old and Ciaran who is twenty five years old. I intend to speak about my father James McNeish who was born on the GRO-C 1926 and passed away on the GRO-C 1995. I will speak about the nature of my father's illness, how the illness affected him, the impact it had on him and our lives together as a family.
2. I will also mention my other family members who have been infected as a result of this disaster. My two uncles, Robert McNeish and Tom

McNeish, both of whom contracted HIV in 1984 and died within six weeks of each other in 1994. My two cousins Robert Mackie and **GRO-A**

GRO-A were also infected with HIV and my cousin's children **GRO-B**

GRO-B and another cousin both contracted hepatitis C. I will not say the name of my other cousin, because he is not involved with this Inquiry.

3. I have appointed Thompsons Solicitors to represent me for this matter. I do not wish my statement to be anonymous.

Section 2. How Affected

4. Dad was quite a gentle man. He was easy going and very placid. He wasn't argumentative at all. He took his haemophilia in his stride and just got on with things. Dad came from a large family and haemophilia was common amongst them. When he was growing up, he was off school a lot, so as a child, he would do a lot of cooking and cleaning if he was off ill and help my Granny. Dad then went to college in England and then worked with the Civil Service in the Department of Health, Social Security office. Dad became quite disabled in later life. He couldn't bend his legs and arms because of bleeds. He had to wear special shoes, but he just took it all in his stride.
5. Dad and my other family members were all diagnosed with haemophilia A. My father was considered to be severe. I don't know when he was diagnosed with haemophilia, but his medical records indicate that he was a young toddler.
6. Dad had an inhibitor so he didn't always receive treatment. When he did, he received Factor VIII and as a result, he was infected with hepatitis C. The first time he received Factor VIII in the 1970s, he took a bad reaction to it and developed an inhibitor. I exhibit records listing the treatment Dad received as **WITN3477002**. I note that Dad was receiving commercial Factor VIII between 1985 and 1988.

7. The procedure then was to stop treatment with Factor VIII if this occurred, nowadays if you have an inhibitor, the treatment is to bombard the body with Factor VIII. Dad would usually receive porcine or FEIBA, which is pigs' blood when he required treatment.
8. Dad was always reluctant to go to hospital when he needed treatment. He would argue that they wouldn't be able to do anything for him. He preferred to just sit at home and endure the pain of the bleed. I remember he would sit in his chair, or sleep in his chair, depending on where the bleed was. He knew that if he went into the Edinburgh Royal Infirmary and Dr Ludlam got his hands on him, he would be admitted and Dad didn't want that. Later on, we reasoned that this was how he had managed to dodge the HIV bullet. We also thought he had dodged the hepatitis C bullet, but that was not the case.
9. Dad was diagnosed with hepatitis C in 1995 however I can see from the records that Dad was positive for hepatitis C in 1991. This test has been done retrospectively from a sample that was taken in 1987, as a test only became available in 1991. I exhibit a record that shows this as **WITN3477003**. I note that this test result was not reported until 1992 and even then, he wasn't told until 1995.
10. Dad was born in Tranent and lived there all of his life so his GP was always based at Tranent Medical Centre and he was always under the care of Edinburgh Royal Infirmary. I recall he was under the care of Dr Davies and then Dr Ludlam. He only saw Dr Ludlam at six monthly check-ups, otherwise most of his contact with the hospital, was with Rosie Dennis.
11. I do recall that every time Dad went on holiday, Dr Ludlam would insist that Dad take a couple of vials of treatment with him, just to be safe. I remember I was married in 1982, and shortly after then, he went with my Mum, Maureen McNeish, to Germany on holiday. He had to go to hospital there after he hurt his leg and was treated with the vials he had taken over with him. I exhibit records that refer to this under

WITN3477004. I note that after this holiday, it was noted that Dad possibly had jaundice.

12. Dad hadn't kept well for a long time and he started to develop problems with angina. Dr Ludlam wanted to look into Dad's heart problems and do an angiogram. He consulted with a top cardiologist down in London and this cardiologist warned Dr Ludlam that 'if the man is quite happy and has a good life, and managing on angina tablets, that he should be left alone and to not go near his heart'. I exhibit a record that refers to this as **WITN3477005**. Dr Ludlam didn't pursue it again. Dad just took the tablets when he needed them after that, but his health was going downhill. His joints were sore and he had arthritis because of all the bleeds. Getting up in the morning and getting going took a bit longer. Dad took early retirement in his mid-fifties around 1986/1987 because he couldn't manage working anymore. He still got out and about, but his health was very poor.
13. Dad didn't die from hepatitis C. He was diagnosed with it in March/April 1995. He had attended the hospital for his routine appointment where Dr Ludlam told him that he had hepatitis C, but he was told not to worry about it because he was quite old anyway and it probably wouldn't cause him any problems. To my astonishment, in Dad's records Dr Ludlam has recorded that he explained the risks and that Dad may already have cirrhosis of the liver. I exhibit this letter as **WITN3477006**.
14. Dad was quiet closed. He didn't speak about hepatitis C. He didn't want to worry anyone. I don't know what information he was given about hepatitis C but he was asked to go for a liver biopsy which I understand he declined. He did have a liver scan though and he was told that his liver looked fine. I don't know what information he was given about the risks of spreading the infection.
15. After his diagnosis he went to his MP John Home Robertson who was very supportive of Dad and supported the campaign for compensation. I exhibit two letters from Mr Robertson indicating his support as

WITN3477007. Further to this, I exhibit the Scottish Office's response as **WITN3477008**.

16. I found out that he was infected just before he died, probably around August. With the passage of time, I cannot recall the exact conversation now, but what I can recall, is that it probably came up in the context of conversations about his impending operation in 1995 for a polyp. It didn't become an issue though, because Dad died two days after the operation and with everything that happened, my mum and I put it to the back of our minds.
17. I have a letter that Dad was sent in August 1995 offering him an appointment at the combined liver clinic on the 3rd August 1995 which Dad did attend. Shortly after that on the 10th August 1995, Dad received a further letter about a major study that was being conducted on haemophilia care in Scotland to co-ordinate all the people that were involved with the care, physio, liver etc. This letter was asking if Dad would attend hospital for a conversation about his background and for permission to view his medical records. Dad went to this appointment but I don't know what occurred.
18. Not long after that Dad had a problem with bleeding from his back passage, and they took him into hospital. They conducted more tests and the polyp was discovered. It was causing him to bleed quite a lot, so the decision was made, that an operation would be required to remove this polyp. Dad went into hospital on September 26th 1995 to have this operation which was very successful because they had a new factor treatment, Factor VII. It was an expensive treatment but they decided to try this on Dad rather than attempting Factor VIII because they were getting really good results with the clotting. Unfortunately because of the problems with Dad's heart, which we knew nothing about, after the operation Dad took really ill and died on the 28th September 1995 on his 69th birthday.

Section 3. Other Infections

19. I am unaware of Dad having contracted any other infections other than hepatitis C. I note that Dad was tested for HIV in 1984 and was negative. I do not know if he knew, that he was being tested for HIV. I exhibit this record as **WITN3477009**.

20. I also note that Dr Ludlam wrote to Dad's GP about the risks of HIV in 1985 but I cannot locate a similar record of this being discussed with Dad himself. I exhibit this letter as **WITN3477010**.

Section 4. Consent

21. From what I have heard from the other infected and affected people at the hearings, I do believe Dad has been tested and treated without his knowledge. Dad couldn't have been that lucky that Dr Ludlam liked him that much, that he didn't use him for his own purposes. Up until now, Mum and I wouldn't have said a bad word against Dr Ludlam. The hearings have been eye opening.

22. After discussions with other people at the hearings, I do believe it is possible that Dad was used for research purposes.

23. When Alice Mackie spoke about the cohort when she was giving her evidence in July 2019 it was eye opening about people being used for research. I have always wondered why Dad never developed HIV when two of his uncles and two of his cousins did. The first time Dad received Factor VIII, he had a really bad reaction to it. I would like to know if this is when he was infected. I have now discovered that Dad was being treated with commercial Factor VIII and was invited to take part in a skin test in 1992. I exhibit this letter as **WITN3477011**. I also note that Dad was on a human genetics register, which I was not aware of. I exhibit a document about this as **WITN3477012**.

Section 5. Impact

24. When I think about it now, there were a number of times when Dad wasn't feeling well and he was quite tired. My Mum was the type of person that liked to be out and about so Dad would take her places, as she needed, as they were both retired in the late 1980s. Dad started saying that he couldn't be bothered and there were obviously days when he was feeling tired and lethargic. It could have been to do with the hepatitis C as well as his haemophilia.

25. The heart issues that Dad had were never confirmed to be directly connected to hepatitis C. When he died, the hospital asked if they could do a post mortem on him and Mum refused. Her opinion was that they had done enough to him. Of course she never thought that all this information would be needed so many years later. I exhibit a letter that Dr Ludlam sent to a pharmaceutical company describing Dad's death as **WITN3477013**.

26. Dad's liver function tests were coming back near a normal range so he didn't need any sort of treatment. I don't think he would have taken it if it had been offered though as both my uncles had taken treatment. My cousin had taken it as well and he saw how ill it made them. Dad's philosophy was, 'what will be, will be' and he wouldn't have wanted to be desperately unwell. I do note that it is written in his records that Dad was unsuitable for interferon treatment because of his heart condition. I do not know if this was discussed with Dad. I exhibit this as **WITN3477014**.

27. Before Dad was diagnosed, we did of course have a number of other family members who were infected and died. The effect on our family was devastating. We were a close family and saw each other regularly. We didn't see our cousin Robert Mackie that often though.

GRO-C

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They knew how they felt about Dr Ludlam. Robert

couldn't get his head around why my Mum and Dad couldn't see what was going on. My Uncle Bobby wouldn't have said a bad word about Dr Ludlam either and because of that, Robert and Alice cut themselves off from the Tranent arm, of the family. I lost a cousin that I could have had. We see each other now and again, but it's not a relationship on the same level as my other cousins.

28. My Uncle Tom and Uncle Bobby were both in hospital at the same time towards the end of their lives. They were lying beside each other when Uncle Tom died. That was in GRO-C 1995. Uncle Bobby was so ill, he couldn't even go to my Uncle Tom's funeral. That was when Uncle Bobby said he wanted to die at home, which he did, in GRO-C 1995.

29. I recall when all the media campaigns existed around AIDS, even then our family didn't talk about it. My family didn't get any sort of negative feelings from anybody. We were such a big family in Tranent, everyone knew us. My cousin, GRO-B was subject to some abuse. He was younger and I think people who didn't understand gave him abuse, the younger generation. The presumption was that he had haemophilia, so he must have all these viruses.

30. I knew about hepatitis C because Dad had haemophilia. I am a carrier and even before my son was born I became involved with the Haemophilia Society, so I went to lots of meetings. I became a Trustee for the Haemophilia Society in London in 1996 which I did for five years. I was always involved in the Scottish group and then we broke away and formed Haemophilia Scotland. I also became a trustee for Haemophilia Scotland, I have always kept an eye on things within the Haemophilia Community.

31. GRO-C

GRO-C

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GRO-C

33. After I gave birth to Ciaran, I haemorrhaged severely and the doctors came to me immediately and said that they would really like to give me a blood transfusion. I refused. The doctors tried to reassure me, saying it was safe. I still refused because of my family history. I asked to go home on iron tablets, but was told I would be on them for months. That was fine with me. I got home and I was only in the house for about an hour or so when the phone rang. It was the doctor from the Western General Hospital, Edinburgh to say that I had been given a choice the previous night, but I needed to return straight away because my blood count had dropped really low. I went back and I received three units of blood. I felt really mixed about it.

34. I had always donated blood throughout my life. Despite being told the blood I received was safe, it was announced that people who had received transfusions before a certain date, would not be able to give blood anymore, so now of course I can't donate. They still took my blood for a time after I received the transfusion though. It never tested positive for anything and they still took it.

35.

GRO-C

GRO-C

36. Ciaran missed out on so much with not having his uncles and my dad.

He could have learned a lot from having them around, GRO-C

GRO-C But of course, we have lost them and Ciaran as a teenager, thought he was invincible. My uncles and Dad were badly disabled as a result of not having treatment when they were younger. Ciaran didn't see anyone who was disabled growing up. GRO-C

GRO-C

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GRO-C Ciaran was born in the January and my two uncles died in the May and July that year. That was a very hard year. I remember Uncle Bobby came up with a present for Ciaran after he was born, and he just looked terrible, absolutely ghastly.

39. Mum was devastated when Dad died. They were together all the time, and were married for thirty nine years. They had been planning to go to Australia to celebrate their ruby wedding anniversary in January 1996 and that all had to be cancelled. Mum can't believe that doctors would do the kind of things, that Dr Ludlam has done to my family.

40. One of the other participants at the Inquiry Hearings, who knows our family well, was speaking to us when the topic of Dad came up. I said to him, that I had no idea how it was, that Dad managed to avoid getting HIV. His response to me was "Your Dad was one of the nice ones". I try not to think that this was the reason that my Uncle Tom and Uncle Bobby were infected. That they were guinea pigs and maybe Dad wasn't, was it that? Was it that he liked some people more than others and cherry-picked? My Uncle Bobby and Uncle Tom were really nice people as well.

41. I started to work as a nursery nurse, in the same school that Ciaran attended, GRO-C

GRO-C

42. GRO-C

GRO-C

 We did and he was wonderful, totally understanding. He gave the answer that I expect every dentist to give, when faced with this. "I treat everyone, regardless of infections, so I do everything I should, to keep everybody safe". That was very reassuring and it should be the response of all medical professionals.

43.

GRO-C

44. I can't ask Dad questions; GRO-C which makes me very sad. I miss him a lot, it's been twenty four years this year since he passed.
45. I remember the gravestone adverts in the late 1980s. They were getting a message across, but this was people's lives they were messing with. At the time, I worked with social services in Edinburgh. I worked in Craigmiller, in a children's centre and we were one of the centres in Edinburgh that took on a child with HIV from a drug addicted mother. I had a lot to do with that child, I used to take them for their appointments and things at the hospital. When my uncles were diagnosed, I treated them like anyone else. I understood the infection.
46. Dad retired in 1987 from his occupation as a clerical officer with the Civil Service. He worked with the Department of Health and Social Security. That was the other thing in Tranent, we used to get a lot of people coming to the house and asking him to give them advice about their benefits. He was well thought of in the community. When he retired, he was definitely ready though and wanted to have more family time.
47. I had to change jobs after Dad passed away. I used to work in the Sick Kids Hospital after I had Ciaran. I worked twelve and a half hour shifts and some nights I would get home from the hospital and I would just have to go right back to the hospital again. When Dad was there, it was manageable but after he passed, it was too much. That is how I ended up changing jobs to working as a nursery nurse with a school.
48. I have noted that in Dad's records, the Co-Operative Insurance have written to Dr Ludlam in 1988 asking Dr Ludlam if Dad had been exposed to HIV. I exhibit this letter and Dr Ludlam's response under WITN3477015.

Section 6. Treatment/Care/Support

49. Dad didn't face any obstacles, and if he had survived for longer than he did, receiving care wouldn't have been a problem for him, he was a nice guy. Counselling for the family would have been good though, or it would have been good for the family to have had the option. That was not available back then.

Section 7. Financial Assistance

50. It wasn't until the Inquiry really came to light and it was starting to get more momentum did I look into the scandal further. We had spoken to GRO-A and GRO-A came out to my mum's house and spoke to her and to my auntie. My auntie had been in touch with the Skipton Fund and had received money. Mum and I spoke about this, and we wondered if she was also entitled to money. Although Dad had only been diagnosed shortly before he died, he was still infected.

We don't know how the illness would have progressed for Dad had he survived the operation. Dr Ludlam said to Dad, when he was diagnosed that it was fine because he was older, but what gave him the right to decide that, when he didn't know either? I recieved the forms and sent them off with Mum's signature. Rosie Dennis filled out the forms in support of the application as well and Mum received the money. It was just at the point when the Skipton Fund was changing over to the Scottish scheme.

51. I have always known about the Skipton Fund because of my involvement with the Haemophilia Society, as I was a Trustee. I had put it into the back of my mind though, because everything occurred in such a short space of time for Dad and he wasn't "ill". As time went on, I realised that Mum must have been eligible as well.

52. Mum received £50,000 in December 2018. She feels like she shouldn't have the money though, because Dad isn't here. She feels like she has more money than she has ever had and Dad is not even here to share it with her. She also receives a monthly sum of about £200 a month. The monthly sum was also backdated, to the amount of £1000. I feel she should have had this backdated to 1995, at the very least though.

53. There weren't any difficulties or obstacles in the application process however no one has ever tried to contact Mum about this money and her entitlement over the years. It has always been me pushing her forward with this. She is eighty four now.

54. Generally there is never enough money for the infected and affected. I know the Government don't have an infinite pot of money. I remember when my Uncle Bobby got a bit more than £20,000 from the Government after his HIV diagnosis. The amount was a bit more, because he had a child. My Uncle Tom got the bare minimum because he was on his own. That is no way to treat somebody. What did that money do? Yes they survived for ten years but that money didn't fully support them for ten years.

Section 8. Other Issues

55. I have no other issues to raise for the Inquiry's attention.

Statement of Truth

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

GRO-C

Signed Carolyn McGimpsey (Jul 8, 2020 17:58 GMT+1)

Dated Jul 8, 2020