18 JAN 2019

Witness Name: Neil Rutherford

Statement No.: **WITN0133001**

Exhibits: **Nil**

Dated: 9 January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NEIL RUTHERFORD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 October 2018.

I, Neil Rutherford, will say as follows: -

Section 1. Introduction

1. My name is Neil Rutherford and my date of birth and address are known to the Inquiry. I am employed and work in the Telecoms sector. I am married and have two children, aged 14 and 12.

2. I confirm that I have chosen not to have a legal representative and that I was happy for the Inquiry team to take my statement. This statement is made from the joint recollections of myself, my father, and my elder brother.

3. My mother is Anne Rutherford who passed away in June 2015 at the age of 72. In this statement, I intend to speak about my mother's infection with the Hepatitis C virus. In particular, I will talk about the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our life together.

Section 2. How Infected

4. In the mid-1980s, my mother was receiving treatment for Non-Hodgkin's Lymphoma, a form of cancer.

5. Around 1984 / 1985, she was given a blood transfusion at the Cancer Ward of Glasgow Royal Victoria Infirmary. The Consultant, Dr. Tansey, recommended the transfusion. This was alongside other treatments such as a bone marrow transplant.

6. I am not sure over what period of time the transfusion was given and how much was given. I believe red blood products were provided as her treatment was interfering with body's ability to produce healthy red blood cells. I am unaware of my mother having an operation: her treatment I believe was based primarily on chemotherapy and/or radiotherapy.

7. My father is not sure what form of discussion took place between the doctors and my mother as regards receiving blood during her treatment, as he was not present during consultations at her request. I believe she had a good relationship with her doctors (and spoke highly of them) and would likely have been told that the transfusion(s) was the best treatment at the time.

Discovery of the Hepatitis C virus

8. In believe sometime in the early 1990s, my mother had some tests carried out. Something showed up on the tests and she was asked to attend the **Glasgow Royal Victoria Infirmary hospital**. My father believes it was Dr. Tansey (her treatment Consultant) who verbally informed her that she had the Hepatitis C virus. My father was not present for the discussion. There was no offer by the medical staff to speak to my father. As he was not present for the discussion, we do not know what was said and/or shared between Dr. Tansey and her.

9. In terms of the impact of her Hepatitis C diagnosis, I believe my parents talked about the risk of infection from physical intimacy GRO-C

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10. My mother was fully well aware that the Hepatitis C virus would impact upon her life, likely shortening it given the impact it could have on her liver. In many ways, my mother's approach was to accept the diagnosis and look to live her life to the full/ the best she could. She took a number of positive steps to change her life to essentially aid with prolonging it: she stopped drinking and went on a primarily plant and fish based diet. She believed that this would be beneficial. It did, however, change her social life and interaction with friends.

11. She was relatively capable and fit for most of her life but during the last years of her life, her health declined markedly. She found physical activity, even walking more difficult and began to feel more poorly, suffering further medical complications. As she approached the end of her life, and her liver function declined, her general health declined even further and her skin took on a jaundiced complexion.

12. In June 2015, my mother passed away at the age of 73 from cirrhosis of the liver, which was caused by the Hepatitis C virus.

13. Before she passed away, she was at Dundee Ninewells hospital for 2-3 weeks. The medical staff tried various treatments such as kidney dialysis, drugs and other treatment.

14. The nursing staff were excellent. In terms of the Consultant staff my feeling was they did not engage very well with her or my family - she moved ward a number of times and my father faced difficulties in getting access to / information from the doctors. Whilst appreciating they were busy, it felt at times they were not focussing on her treatment or attempting to remedy the situation.

Section 3. Other Infections

15. My mother was only infected with Hepatitis C and no other viruses through the blood transfusion(s).

Section 4. Consent

16. I am not aware if my mother consented to the Hepatitis C test. We only know that the virus showed up on a subsequent test result.
17. I believe my mother consented to the treatment of the Hepatitis C virus.

Section 5. Impact

Mental and physical impact of the infection

18. After the diagnosis, my mother had regular tests and biopsies, which suggested that her liver for most of her life was stable and performing to a relatively good level. I believe she went back every couple of years for a liver biopsy.

19. My mother's health was fine for most of her life

post her diagnosis: she continued to work, help and volunteer following the diagnosis.

20. However, as time went on, physical exertion was difficult, there was discomfort and soreness of her body and her general health declined.

21. My mother was very stoic. She didn't really talk about the infection when I was growing up, it wasn't really a big thing - life just carried on and she didn't let it define her. I feel looking back that she got more frustrated by the virus as it had more of an impact upon her life and her physical capabilities. That said, she continued to look after, see and spend time with her family, grandchildren and friends.

22. I now understand that she suffered from bouts of depression brought on by having the virus. I wasn't aware of this, given she hid the symptoms, however, my father saw it given his relationship with her and spending more time with her. For me, I largely only saw the physical side of the virus in later life.

Other medical complications as a result of the infection

23. My mother did have other underlying health issues unrelated to the Hepatitis C virus. However, these did not have the same damaging effect the Hepatitis C virus had on her life.

Treatment for the infection

24. My mother had regular biopsies to check her liver function, and performed generally well over much of her life.

25. As medication was developed / new products became available, my mother was offered the chance to try to alleviate the symptoms of the virus. Among those, she was offered and took Interferon. I'm unaware of the doses, however,

she was not on this treatment for long - a matter of weeks.

26. She made the decision to stop the treatment given the debilitating side effects, which actually limited her ability to live her life. She did not believe the supposed benefits were worth the impact they had on her.

27. The physical side effects were numerous: amongst those, she was sick and dizzy - she just couldn't operate. Beyond that, my mother rarely spoke about the mental side effects of her treatment.

28. Subsequently, alternative treatment was offered but my mother did not want it due to her previous negative experience with Interferon. As far as I am aware, she was never cured of the Hepatitis C virus, and indeed it was the main contributor of her death in 2015.

29. I believe my mother did not have any problems with accessing the treatment and continued to have check-ups and engagement as regards her condition as her life progressed.

Medical and/or dental care

30. My mother disclosed her infection to all her medical professionals and they were happy to treat her. She was never denied any care as far as I'm aware.

My mother: Impact on private, family and social life

31. My mother only spoke to 1 or 2 of her close friends, who were going through similar cancer treatment, about her health. Those close to her in this way helped her. Disclosure did not really change anything, she was sociable and engaged with others. Whether people understood the virus I don't know, but they still accepted her for who she was. Today access

to information would be readily available on the internet, however, this information in the 90s was more limited and so the understanding of the virus was much less. This could have caused adverse views from friends (but it didn't as far as I'm aware).

Personal: Impact on my private, family and social life

32. I found out about my mother's condition in the 1990s. I think I was at university at the time and not at home. It was introduced in a soft way. I already knew about the cancer and after finding out about the Hepatitis C, it was almost like "This is what it is and you move on". After that for many years it wasn't discussed or brought up.

33. I've never really told anyone about the infection and didn't really think to raise it with people. Recently it has been more of a point of discussion as more awareness about what happened becomes public. It never stopped me from living my life, nor would my mother have expected it to. My mother wouldn't have accepted me not doing things due to the virus. She would very much say, 'You have to live your life and go on and do things'. It was her view of the world. To me, we continued to function as a normal family but clearly there was the virus and its effects in the background.

34. I know the diagnosis of the virus changed my mother's lifestyle and the reasons were explained to me. It was never really a big thing. My mother was the type of person who would say 'This is what has happened and you carry on'. I understand more about it now and believe that it feels like others went through worse than we did when you read other survivors' and their families' stories.

35. The last few years of her life were more difficult -

you could see her deterioration. Regardless of that she remained very active with all of her grandchildren and loved to see and spend time with them. For me it was the bit at the end that impacted me the most - the realisation that what Hepatitis C meant for her and how it had impacted her life. She should have lived for a much longer time and enjoyed both her children and grandchildren growing older.

Family: impact of their private, family and social life

36. My father was the one primarily present during her treatment, diagnosis and as their life continued. He was given only so much insight into everything, but was more aware of the mental impact it had on her. GRO-C GRO-C He was also always there for her and her passing has been a painful period for him. His life changed and will never be the same.

Education

37. My mother was diagnosed with cancer in the mid-1980s and with Hepatitis C in the early 1990s. This had no impact upon her education for her as the diagnosis was made after she completed her studies.

Work-related effects

38. In terms of work my mother returned to work after her treatment for cancer. She primarily worked in the childcare sector. Her only period of discrimination was when she was a teaching assistant for a local authority outside Glasgow. She disclosed her diagnosis to the Authority as her employer from the outset.

39. Whilst I wasn't party to the detail, my father

described how she effectively had her employment terminated subsequently due to discrimination around the Hepatitis C virus. Her employer's response was 'You have Hep C so we can't keep you on despite knowing that she had the condition previously. She lost her job because of this action.

40. My father was angry about this reaction from the employer and even talked about legal action. My mother said that it was not worth it and it wasn't taken any further. She just accepted it, left it behind and moved on. She loved her job but sought out other opportunities and secured other employment not long after.

41. She continued to work and volunteer with children e.g. at nurseries and through church and always disclosed the infection.

Financial impact

42. There was no impact on our family's finances given the roles of my mother and father. My father worked in finance. He had time off to help my mother manage her treatment. As a result he continued in professional employment and was the main earner. If it were the other way around, then it may well have been very different.

43. There were, however, financial implications from the virus. This included elements such as additional costs of insurance for going on holiday. This didn't stop them going but made holidays much more expensive.

Section 6. Treatment/Care/Support

44. During the time of the virus, I was never offered any form of counselling or psychological support. I don't believe my father or brother were either.

45. My dad learned what he could from speaking to

my mother and others when he got the change. None of us were ever offered any testing at any stage.

Section 7. Financial Assistance

46. In 2003, there was an announcement that a fund would be made available for those affected by infected blood products/ blood. We were in contact with the Scottish government and Malcolm Chisholm MP (and his staff), who was the health minister at the time, to find out more. A promise was made that information would be provided when available. An email was subsequently received advising that the fund was open. I believe this was the Skipton fund.

47. In 2005, my mother applied to the Skipton fund. My brother helped with the application process. The process was straightforward - there was a form and the NHS was approached for verification. There was a requirement for supporting statements / evidence of blood transfusions from the NHS as part of the process. I have not seen any of the documents as they were submitted by the NHS on her behalf. My mother did not need to provide any further documents or information.

48. Within a period of months, confirmation of a payment was received, alongside a remittance. A payment from the fund came through. This was received when she was alive.

49. After my mother passed away, my brother applied for a further payment in line with the scheme rules and provided her death certificate with the form. It was not a very long process, taking perhaps around 2-3 months.

50. A further payment was made as the NHS advice states Hepatitis C as the cause of death. The payment went into the estate. The key

precondition applied was that the deceased family member had to have passed away due to the effects of the Hepatitis C virus.

51. In 2016/2017, my father applied to the Scottish Infected Blood Support Scheme. A form was completed and my mother's death certificate was provided. The process again was streamlined and did not take that long. It was not means tested. He now receives funding, which finishes upon his death. The primary condition on his annual payment is that they will stop if he remarries or co-habits with someone else.

52. In terms of observations, I find the timing of these payments to be skewed - there seems to be more money as a form of recognition of an early death rather than supporting people to live their life or fund additional care to improve their (and those around them) quality of life. Surely the focus of the funding should be during someone's lifetime to assist with spouse / other family members providing assistance and care, meeting the additional costs of having the virus and, for some, as compensation for a loss of being unable to work due to becoming infected and ill.

53. For us, regardless of the money received, life carried on as a normal family. I believe we may have had a very different experience to other families due to the financial position of my parents. If the situation was reserved, it may have been very difficult. It would seem to me much better to get financial assistance during a lifetime to pay for a quality of life (which would have been lost due to the infection) and any additional costs arising from the virus.

54. In terms of the funding as well, I think my mother's approach to the virus tempered her views. For her, life carried on and she didn't let the virus define her. Rather than receiving the

funding / compensation, spending time with her grandchildren, for example, was worth more.

Section 8. Other Issues

55. I do not have any other issues to raise.

Statement of Truth

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

Signed GRO-C

Dated 10/1/19