Statement No.: WITN7357001

Exhibits: WITN7357002

Dated:

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7 October 2022.

WRITTEN STATEMENT OF MICHAEL PAYNE

I, Michael Payne, will say as follows: -

Section 1: Introduction

- 1. My name is Michael Payne. My date of birth is GRO-C 1963. I am 59 years old and live in GRO-C Scotland. I am married and have three children aged 29, 28 and 25. My eldest moved out last week, my middle child still lives with us and the youngest lives in GRO-C. I retired from the army having served in the Royal Signals. Following that I was a telecommunications engineer and am now pretty much fully retired.
- 2. My father Stanley Payne, aged 86 is here to assist with this statement. My father lives in GRO-C Scotland. I have a brother, aged 56, who is a GP in GRO-C
- 3. I intend to speak about my mother's Hepatitis Infection ("HCV"). My mother's name was Margaret Helen Payne. Her date of birth was GRO-C 1941. She

was born in Scotland and was an officer in charge of a residential home. She trained to become a nurse for 3 years before meeting my dad. Mum died in March 2003.

Section 2: How affected

- 4. Mum had an operation on her foot to treat a melanoma at Dundee Royal Infirmary in GRO-c 1990. It was my wedding day on GRO-C 1990 and mum had delayed her operation to GRO-C 1990 so she was able to be involved in the ceremony.
- 5. She had another operation at Gartnavel Hospital, Glasgow in July 1990 to remove lymph glands in her groin area. During this second operation, she received a blood transfusion.
- 6. Dad recalls she was in Gartnavel Hospital for at least a week as he was dealing with everything in her absence. He remembers he had his car stolen whilst visiting her as it was parked near the hospital.
- 7. Following the operation, mum was in a lot of pain and was unable to walk for several months. She didn't return to work at the residential home until November 1990.
- 8. Two weeks after she returned to work, mum started showing symptoms of HCV. Over the next couple of years, she had several blood tests and finally a liver biopsy which showed she was HCV positive. It wasn't until 1992 that she was informed she had Post-Transfusion Chronic Hepatitis C.
- 9. Mum never communicated the symptoms or what she was feeling with us; she protected us from all of that. Everything we know has been because she was so good at keeping records of letters and communications she had with doctors. I know she was worried about her job or giving it to the elderly patients

she worked with, however, the GP assured her that transmission was not possible.

- 10. She was prescribed Interferon for her HCV by Dr Alan Shephard, Haematologist at Perth Royal Infirmary in 1995, almost three years after her diagnosis. Neither my dad nor I recall how the injections were administered. We do not remember seeing her administering them herself. Since dad was working throughout this time, it is likely mum drove herself to hospital for this treatment. Especially since I was married by GRO-C 1990 and my brother was away from home studying in Dundee.
- 11. Documentation mum retained shows the treatment was halved in dosage within a month because the effects were so severe. By December 1995 mum had resigned from her job at the residential home.
- 12. The HCV symptoms, according to the doctors, had impacted her thyroid gland. Mum complained of numbness to her face, constant flu-like symptoms, yellow skin, extreme tiredness and the need to rest all the time. The doctors had treated her for thyroid problems, however, these symptoms persisted.

Section 3: Other Infections

13. I do not believe Mum received any other infections other than HCV through infected blood.

Section 4: Consent

14. When mum was given a transfusion at Gartnavel hospital, dad doesn't now recall that she was informed of the associated risks. Neither he nor I are able to say whether the issue of consent was ever canvassed with mum.

Section 5: Impact

- 15. Mum was off work for some time due to ill health and eventually gave up her job due to pressure from work. She resigned in December 1995, towards the end of her interferon treatment. I believe it was a combination of her taking time out for her HCV symptoms and the interferon side-effects, as well as, the risks associated with working in a care home environment with a viral infection that led to her giving up work. In those days, there was a serious stigma attached to HCV which was often interpreted as akin HIV. She never spoke openly about it but I recall she took a lot of time off and handled it her own way.
- 16. When mum received the initial HCV diagnosis we were quite confused as we didn't know what it was. We always thought it was something she'd have cured and we'd all move on. We were mostly shielded from what she was going through, especially since I was away with the Army and did not return until October 1997. She always reassured us that she was getting the treatment and remained positive that she'd recover. We were also reassured by the fact that she was having regular checks so were equally as shocked when we realised her cancer had been missed all these years. She could have lived with the HCV but we couldn't do anything about the cancer.
- 17. When Mum was diagnosed with HCV, she was provided with advice on the necessary precautions she should take. Whilst we were made aware, and I know my brother would definitely be more aware of how it's transmitted, Mum always worried about the little things. She was always concerned about passing it on to family members. Dad mentioned that their private life was drastically impacted and even things like a kiss and a hug were done with caution. He said the thought of transmission always hovered around them. Mum was particularly distressed when she spent time with her grandchildren as she did not want to hurt them in any way. I have 3 children and my brother has 4 and following her diagnosis of HCV mum would be reluctant to give them a cuddle. She also adored them and loved to be in their company so I can imagine that was particularly difficult for her.

- 18. One of the hardest things is knowing that she was not able to do the things she loved. She loved planning family days, spending time with her grandchildren, being involved in the community and once she became ill she was not able to do any of that. I remember she came over for one of my children's birthdays and had to go upstairs to sleep as she was so tired. I recall having a family lunch in GRO-c in Easter 2002. That was the last time the whole family were together. At that point she was very tired and it was rare we'd go out like this. We began to visit her as opposed to her coming to see us.
- 19. Watching her deteriorate was one of the reasons I left the Army. I signed up initially for 6 years and stayed on for nearly 13 and half years, but I gave it up so that Mum could spend more time with me and the family. I was still positive and she always shielded her family from the actual reality. My brother was living with her and was more aware of how far along Mum was. However, it wasn't until I read these letters after her death that I realised how bad it actually was.
- 20. Mum was 61 when she passed away. Dad was born in 1936 and he's here and Mum was much younger than him. She should be with her husband right now because she was so special to us all. Dad retired in August 2001 and Mum was diagnosed with cancer in September 2001. Dad took care of her until her death in March 2003.
- 21. Dad was lost without Mum. He says the first two years were the hardest as he didn't know how to do anything for himself. He was living alone and still is. He now tries to stay busy and is looking after my Mums' late uncle's estate.
- 22. We did not have any issues with funeral preparations when Mum died. She passed away at home and the funeral parlour was very helpful and allowed us to go and see her.

Section 6: Treatment/Care/Support

- 23. Mum's interferon treatment started in July 1995. After six months of interferon treatment, the Hospital said that the treatment had stopped replication of HCV. She underwent regular tests throughout 1997 to 1999 and a letter dated 18th July 2003 from NHS Scotland stated that during that period those tests came back negative for virus replication.
- 24. After she resigned from her job, she took a part time office job with Crossrords Care Attendant Scheme. I found a letter from them dated 22nd July 1998 which said "I visited Margaret when she received treatment, she was extremely ill, but she continued to fight back after 6 months of treatment and make a life for herself, she was offered therapeutic work with the scheme".
- 25. Mum loved to keep busy so having these symptoms really impacted her negatively. In a letter to her doctor in July 1998, she complained of pain and tightness in the right side of her chest which spread to her back. She stated her right cheek, ear and forehead also hurt which spread to the back of her head, neck and skull which always felt sensitive, numb and began to irritate to a point where she felt she might be experiencing a stroke. In a note left by her she complained of trouble swallowing which often made her cough. She went on to say "It is very tiring fighting these feelings...it is unfortunate that the medical profession has been unable to diagnose and give a name to my illness and no one takes my illness or how it affects me seriously. I have worked hard and never taken a day off and never claimed benefits. I just want to feel well enough so I can get on with my life".
- 26. I remember mum saying during this time that she needed regular rest and would have to lie down after she'd gone to see her friends. I recall when she would visit us, she would need to rest and this limited what we did together. Whenever she took her grandchildren out, whom she adored spending time with, she would be exhausted when she'd return. Before her illness she ran church coffee mornings and Saturday clubs for the elderly where she'd

organise entertainment for the old folks homes. She was often singing for them or giving them haircuts. She also worked for the YWCA where she organised events. Once the interferon treatment began, all of this was limited and eventually stopped. She participated fully in the small town community.

- 27. Around February 1998, Dr R J Swingler at Dundee Royal Infirmary said he had taken the opportunity to review mum's brain scan and described it as satisfactory. He stated the symptoms she'd complained of could often be a side-effect of interferon treatment.
- 28. Mum was having scans every six months and was supposed to be kept under observation. They were focusing on the HCV symptoms and weren't looking out for cancer, regardless of her previous melanoma operations. It wasn't until September 2001 that a doctor at Ninewells Hospital confirmed that mum had Metastatic Melanoma which was not localised. It transpired that one of the scans and MRI's she was having didn't use dye which would have better detected her cancer and provided an explanation for her symptoms.
- 29. Due to her HCV and interferon treatment, she was not able to get the full dose of the necessary chemotherapy. Had she received the correct chemotherapy it may have given her a chance to have a few more years of life. The doctors had initially given her six months to live. In fact, she was with us for 18 months more. She did, however, receive radiotherapy treatment.
- 30. It wasn't until December 1996, in a letter from NHS Tayside to Mums GP Dr McCay, regarding a Hepatitis C look-back study where Dr Galay, Director of East Scotland NHS, suggested that Mum receive counselling following her diagnosis. I don't believe she took it because by then she had become relatively accustomed to her symptoms.

Section 7: Financial Assistance

- 31. Mum was part of a group action consisting of 20 claimants who had received infected blood post-1989. She received her first letter relating to legal action in May 1997. The group action was organised by Hasties Solicitors, York Place, Edinburgh and the group action was called "Hepatitis Group Scotland". In a letter dated 7th May 1997, Hasties Solicitors spoke about a Mr Donald, who had advised that only those claimants who received transfusions before 1989 or whose HCV status had been identified after 1989 would likely be successful. This was part of a decision by the Berlin Supreme Court and based on an EU directive. Since Mum received the transfusion in 1990, she would be included.
- 32. The solicitors mentioned the English Test Case but did not provide any information on how the group action may be impacted by that decision. At no point did the solicitors say whether Mum was entitled to any financial assistance from the government. It was our understanding that the schemes set up by the government were for haemophiliacs who had received plasma products only.
- 33. In a letter received from Thompsons Solicitors and Advocates, to Hasties Solicitors, dated 01 June 2006, they said that the Skipton Fund was available to those who had been infected with viruses such as HCV, but that there was a cut-off date of 29th August 2003. This meant that anyone who had passed away prior to this date was not eligible to apply. Since Mum passed away in March 2003, she did not qualify. Albeit the letter did mention that this was being challenged by way of Judicial Review, we received no update.
- 34. Mum and Dad had stored articles regarding this and in one a Campaigner stated that this was wholly discriminatory. Frank Dolan stated that this plan discriminated against those who had been infected but fell outside of this window. He asked why that date was pinpointed. I agree, the date was completely arbitrary and we were never given an explanation as to why it existed.

- 35. In a leaflet we received from the Skipton Fund the eligibility criteria said that those who had received HCV infected blood prior to September 1991 were eligible. (WITN7357002). Mum would have fallen within this category. But we received this information much later.
- 36. In a letter from NHS Scotland, dated January 2004, it informed us that Sandra Falconer believed that since Mum died prior to August 2003, she would not be entitled to the Skipton Fund payments. She advised that perhaps Mum could make a claim under the Consumer Protection Act 1987. We didn't make this claim, nor was it explained to us what this meant.
- 37. In a letter dated 26th June 2003 from her solicitors Hodge Solicitors LLP, we were sent an offer to settle for £8,000. In January 2008 they increased this offer to £12,000 of which the solicitors took £2,000. We accepted this final payment.
- 38. In total Mum and Dad had paid about £2,000 to Hasties Solicitors for the group action and once it was dissolved in July 2005, a sum of only £429 was paid back. Throughout the group action Mum felt very let down. Dad recalls there was an element of a lack of interest in what happened to Mum. She said she went in circles to get answers and no one would get anything done.
- 39. I don't believe it was about the money. Mum just wanted to be acknowledged and for someone to take responsibility for what she was going through. It affected dad immensely and supporting her through it GRO-C Mum died without knowing that her claim was concluded and that she'd been awarded the £12,000. She died fighting.

Section 8: Other Issues

40. Had Mum not kept these records, we would have never known all this information. After her death, Dad included his own notes and subsequent letters.

- 41. It's frustrating that there wasn't a register kept of people who the NHS knew had been infected. The look-back exercise which took place in 2006 would have been the perfect opportunity for this, to make records which would have helped everyone struggling to prove their infections today. We were never told what the results of that look-back was. Since so many records have been destroyed it wouldn't have been unreasonable to expect that the NHS would have at least kept records of infections or probable infections through infected blood.
- 42. The timeline and work that goes into making a claim or claiming compensation from a scheme is exhausting. Mum had to gather her own information, records, letters with decisions and she still did not succeed in her lifetime. It shouldn't be up to the victims to gather everything. Mum's letters and records began in 1997 and didn't finish until 2008. She was active in finding out what she could do and it really disappointed her. She eventually lost her drive. She was frustrated as everything seemed like a dead-end, a barrier and no matter how hard she worked, she could not get the recognition or acknowledgement she needed.
- 43. This led to a cynical attitude amongst the family that they were just waiting for people to die so they wouldn't have to deal with it. Mum should have had that cathartic feeling that her matter was concluded. She should have died knowing what had happened to her.

Statement of Truth

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

