Witness Name: David James Ashworth
Statement No.: WITN5686001
Exhibits: **WITN5686002**
Dated: 03 February 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DAVID JAMES ASHWORTH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 October 2021.

I, David James Ashworth, will say as follows: -

Section 1. Introduction

1. My name is David James Ashworth. My date of birth is GRO-C 1947 and my address is GRO-C GRO-C

2. I am married and have two grown-up children, one daughter and one son, from a previous marriage. I retired in 1998, having worked as a manager in local government and within health and social services, at various locations within the UK.

3. I intend to speak about my mother's health issues including her infection with hepatitis C ("HCV"), and the circumstances of her death.

Section 2. How Affected

4. My mother, Ena Winifred Ashworth, was born on GRO-C 1925. I am the eldest of her two sons. My father died in the year 2000.

5. Mum was diagnosed with myelodysplastic syndrome in either 1985 or 1986. Prior to this diagnosis, Mum's health appeared to be fine and as far as I can say, she was able to lead a normal life up until the point when one morning Mum didn't wake up. She was rushed by ambulance to Withybush General Hospital, in Haverfordwest. She was exhibiting classic leukaemia-style symptoms. In hospital, Mum remained in a coma.

6. The clinicians were initially unsure as to how to get her to come around. After testing, they established that her blood was causing her illness, which led to her diagnosis with myelodysplastic syndrome. As I understand it, it is a form of blood cancer. It was explained to me that the platelets in her blood were essentially disappearing and required regular top ups by transfusion. Throughout Mum's illness, I recall that she was actually always treated on the cancer ward.

7. Despite administering a blood transfusion, the doctors were struggling to get Mum's blood and immune system kick-started again. They asked my father for permission to administer a horse serum to Mum, to which he gave consent, as Mum remained in a coma.

8. Three days after receiving the horse serum, Mum suddenly woke up, asking what was for breakfast! After this episode, Mum's diagnosis meant that she required a blood platelet transfusion starting every 3 months.

9. Dr Saleem, who was Mum's haematologist at Withybush Hospital until her retirement in the mid to late 90s, had told Mum and I back then, that the process of platelet transfusions would eventually no longer be effective, at which point Mum would gradually fade away and die peacefully.

10. These platelet transfusions lasted from the time of her diagnosis until around a year before her death. Initially administered to Mum every 3 months, this became gradually more frequent over time, as their effectiveness diminished. Eventually, the platelet transfusions stopped working in 2002, around a year before her death.

11. At this stage, with the treatment no longer being of use and there not being anything else they could do to help her, the doctors wanted to discharge Mum to a nursing home in early 2002. I refused to allow this, having promised Mum that I wouldn't allow her to die in hospital or in a nursing home. The hospital was frustrated with me and were insistent, but I refused permission to allow her to be discharged to a nursing home.

12. Instead, I asked that the hospital give me the money that otherwise would have been given to the nursing home. They reluctantly agreed to this, and I also arranged for Mum to receive an independence payment from social services. I subsequently organised a package of care so that Mum could remain at home rather than being sent to a nursing home.

13. Carers came to visit Mum three times a day for a fortnight plus all night care, and I would go to Mum's house and care for her for the rest of the month. This continued on a rolling basis.

14. On a date between 1996 and 2000 when my Dad died, I remember my daughter telling me that Mum had received a phone call from an HCV research study based at UHW in Cardiff. Mum put the phone call on loudspeaker and my daughter was able to listen.

15. During this phone call, Mum was apparently offered the opportunity to participate in a study of HCV positive patients. I was unsure whether Mum knew about her HCV status at this point. I think that the study was based at a hospital, which was part of the UHW in Cardiff.

16. Mum's decision was to turn down this offer. I think that she felt she had been messed around with enough in hospital over the past few years and she couldn't deal with the travel to and from Cardiff. I know that I

agreed with this decision. My memory from the time is that Mum told me that if the study had been for myelodysplastic syndrome, she would have agreed to take part but she considered the HCV to be secondary at that time.

17. I recall that my daughter, who works for the Cardiff University, contacted the medical school on my behalf after this phone call. The person she contacted said that because of the date when Mum received a transfusion, there was no knowledge of infected blood at the time, and as such there had not been any negligence on behalf of the medical professionals. I think they were implying that her transfusions were post 1991 when blood began to be screened. I believe that this would be incorrect because mum started transfusions well before 1991.

18. Mum spent her last few days of life suffering with excruciating, unbearable abdominal pain and was extremely constipated. I recalled what Dr Saleem had said about a peaceful death for Mum. Sadly, this was the exact opposite. I believe that this was down to the HCV and the attack on her liver.

19. Mum died on 20 April 2003. I enclose her death certificate as exhibit **WITN5686002**. Mum's cause of death was recorded as 'I(a) Myelodysplastic Syndrome'.

20. I strongly believe that Mum's infection with HCV shortened her life. I think she may not have died as soon, just from the myelodysplastic syndrome. I do think that the nature of her death in terms of pain and discomfort were exacerbated by HCV. On reflection, I believe that this hastened her deterioration.

Section 3. Other Infections

21. I am not aware that Mum had any other infections as a result of being given blood transfusions.

Section 4. Consent

22. I am sure that my mother would have consented to all treatment. That said, I do not believe that she would have been informed of any risks associated with contaminated blood, therefore she, or my Dad on her behalf, could not have given informed consent. That said, she needed the transfusions to keep her alive, so what real choice would she have had.

Section 5. Impact

23. Prior to her diagnosis with myelodysplastic syndrome and her later diagnosis with HCV, Mum was happy and apparently healthy. My father had a major stroke in 1978 which caused him to lose the use of his right side. He was unable to speak and could no longer work. He was not intellectually impaired, he knew what was going on. After his stroke, Mum had to take took over as the main bread winner of the household, paying the bills, caring for my father and even learning to drive. Mum worked in a clerical role at Withybush Hospital.

24. Mum was emaciated by the time of her death. Her appearance was yellow and jaundiced, which I believe was due to her HCV infection.

25. I spent a lot of time with Mum towards the end of her life. I was her primary carer, meaning that I didn't necessarily recognise the extent to which she was declining. My daughter however, who saw less of her was shocked by her yellow skin and overall appearance.

26. I trusted Dr Saleem, who was an excellent clinician and took very good care of my Mum. As I have stated earlier in this statement, prior to her retirement in the mid to late 1990s, Dr Saleem told us that ultimately her death from myelodysplastic syndrome would be gradual and it would be like just fading away. Mum's death was painful and distressing. I am sure that it is very likely that Dr Saleem knew of Mum's HCV infection before

she retired, but her forecast regarding the way she would die would have been before Mum's HCV diagnosis. Therefore, this suggests that the HCV was a significant factor in, if not shortening Mum's life, in the traumatic manner in which it ended.

27. After Mum's death, I didn't want a post mortem. Although this was not suggested or spoken about as a possibility, I would not have wanted to put her through this after all she had endured. However, I strongly believe that had there been a post mortem examination, this would have shown damage to my Mum's liver as a consequence of her HCV. This may explain why HCV is not on her death certificate, even though I am convinced that it was a contributory factor in her death.

28. Only a clinician could evaluate the extent to which HCV impacted on Mum's myelodysplastic syndrome. If the functioning of her liver was impaired, which is highly likely, and given the role of the liver in regulating blood quality, then I think it is highly probable that the HCV had a detrimental effect on Mum's condition and hence shortened her life. It is difficult to imagine that it would not have had any effect on her myelodysplastic syndrome, a blood condition.

29. The impact of HCV on Mum's life is masked to a certain degree by her prevailing health condition with myelodysplastic syndrome. I am not aware of anyone sitting down with Mum and diagnosing her with HCV. She never told me, which I find surprising. I can only think that the seriousness of HCV did not occur to her, or was not as prominent in her mind as the myelodysplastic syndrome. I do not believe that she deliberately or intentionally kept it from me.

30. Suffice to say that during Mum's life, I had no idea of the impact HCV had on her mentally or physically, because her existing major health issue probably masked the effects of HCV. Her HCV had little impact on me aside from the manner of her passing. Again, any symptoms were likely masked by her myelodysplastic syndrome.

Section 6. Treatment/Care/Support

31. I am unable to say whether Mum faced any difficulties in obtaining treatment in consequence of her infection with HCV. I am not aware of any issues.

32. I was unable to say for sure whether Mum received any treatment to cure her of HCV. However, after speaking with the Inquiry investigator, it seems that she received none. It was explained to me about the length of treatment, the requirement for weekly injections of interferon and the debilitating effects of treatment. Therefore, I can categorically say that Mum was not subjected to this. It may be that it would have conflicted with her myelodysplastic syndrome treatment, or that she was deemed unsuitable to have such strong medication. I have no idea. This is reinforced by the fact that family members were not consulted about Mum's HCV by clinicians and as a family we did not have a 'conference' about it.

33. I am again unable to say whether Mum was offered or received any counselling or psychological support, though I think this is highly unlikely.

Section 7. Financial Assistance

34. I think that I read about an announcement regarding compensation for victims of infected blood and that this was being expanded to include posthumous payments. I cannot say exactly when this was, though I did apply to the Skipton Fund on Mum's behalf in 2011, eight years after she had passed away.

35. I did not experience any difficulties in applying to the Skipton Fund. My application was supported by Mum's former haemotologist and I found completing the form to be a simple process. I believe that Mum's application was submitted in conjunction with her medical records, probably by her haematologist. I never personally saw them.

36. Mum's application was accepted and we received a stage 1 payment of £20,000, paid to her estate. This was split between me and my brother as beneficiaries of Mum's estate.

37. I have been told that there is a 'levelling up payment' for recipients of stage 1 payments from the Skipton Fund, to bring payments in line with those received in other nations of the UK. I don't know whether this applies to posthumous payments but I believe that it should, as if there has been a move for payments to be equitable among devolved nation's funds, Mum's estate should have benefitted. I have not received any information from the Skipton Fund or the Welsh Infected Blood Support Scheme regarding this levelling up payment. I intend to make enquiries.

Section 8. Other Issues

38. My heart goes out to the people who, through no fault of their own, have suffered as a result of this tragedy. After a career in public service, I understand how things can go wrong. It is a tragedy for all those affected by this and I hope the Inquiry brings some satisfaction to the community of people who were so badly affected and continue to be every day. They have my deepest sympathies.

39. Although I think that HCV contributed to my Mum's passing, she was not destined for a long life due to myelodysplastic syndrome. In fact, she probably survived for longer than had been anticipated when first diagnosed with myelodysplasia. However, her liver failed; I am convinced of that. I cannot say how her existing condition impeded her treatment for HCV but I am certain that her life was shortened by it, regardless of any previous forecast regarding myelodysplasia and certainly her final days and hours were made unbearable by the effects of HCV.

Statement of Truth

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

Signed GRO-C

Dated 3/2/2022.