Witness Name: Helen Rogers Statement No.: WITN5335001

Exhibits: Nil.

Dated:

INFECTED	<b>BLOOD</b>	<b>INQUIRY</b>
----------	--------------	----------------

#### WRITTEN STATEMENT OF HELEN ROGERS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 February 2021

I, Helen Rogers, will say as follows: -

#### Section 1. Introduction

- My name is Helen Rogers. My date of birth is GRO-C 1956 and I reside in Cheshire, and my full address is known to the Inquiry.
- 2. I have two children: Michelle and Andrew, both of whom live relatively close. I work full time as a domestic carer, assisting those at home with cooking, cleaning, and any other household responsibilities.
- 3. I was married to Paul William Rogers for eighteen years. He was born on GRO-C 1953 and I knew him for twelve months before marrying him and neither of us had been married before. I was aware that he had haemophilia A, as did his brother, Phillip.

- 4. I intend to speak about my late husband's hepatitis C (HCV) infection which he contracted from Factor VIII blood products, in particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on me and our lives together.
- 5. I can confirm I am not legally represented and I am happy for the Inquiry Team to assist with my statement.

#### Section 2. How Affected

- 6. Paul was born with haemophilia A and he was diagnosed in 1955. He originally received blood products at 'Old Barony Hospital' and our GP referred him to Manchester Royal Infirmary (MRI).
- 7. I recall he was initially treated with cryoprecipitate in 1977, at the MRI under the care of Dr Delamore. On average I went to hospital with my husband once per month; he was in and out of hospital all the time. If I left him for a minute, the next minute he would be calling my name because he had fallen and hurt himself. It felt like we were in the hospital all the time, but Paul could only receive cryoprecipitate whilst at the MRI.
- 8. We were also given Factor VIII products in hospital, and Paul and I learnt how to administer this treatment at home. I remember having to mix the water in one phial and concentrate in the other. They would usually give him blood products and write down the batch numbers.
- 9. There was one trip to the hospital that stood out to me, as Paul was asked to go in for tests and he appeared agitated and concerned. This was very unusual for my husband, so I knew something was wrong. I cannot recall the year of this appointment, but I'm sure this is how Paul came to know about his HCV. They must have told him since this appointment seemed different from the rest.

10.I cannot say for certain when my husband was informed of his HCV status, but I am aware from his death certificate that one of the causes of his death was liver cirrhosis secondary to hepatitis C. My husband was a very private man and never told me about his infection. Sadly, on 20 October 1996 he passed away and it was only at this point that I became aware of his HCV status.

### Section 3. Other Infections

11.1 do not believe my husband was infected with any other viruses or diseases from the use of cryoprecipitate or Factor VIII products.

#### Section 4. Consent

- 12. Paul never raised an issue about whether or not he consented to treatment or tests.
- 13. In the late 1980s, he volunteered to have a liver biopsy and was one of ten patients with haemophilia selected for the program. I thought they were trialling something on these patients, my impression was they were being used as guinea pigs. However Paul wanted to help and saw value in a study relating to the liver. I remember him bruising very badly after this procedure.

#### Section 5. Impact

14. Paul's haemophilia affected all parts of his life. Physically, he suffered with bleeds and bruising regularly. Approximately five to six years before he died, an abscess developed in his knee, which very quickly turned septic. He was at the MRI hospital for three months, as he required surgery to remove his knee. From there onwards, Paul was left with one straight leg and one bent leg, which meant he struggled to walk and he was mainly stuck in his wheelchair.

- 15.I would say my husband tried to live a normal life; if Paul couldn't get up the stairs, he would make his way up on his bottom. As a family we just got on with things, and I did my best to support his independence. In our house I installed a bannister on the stairs and bought a higher chair for him. This helped him move around more freely.
  - 16. Before I met my husband, he worked as a petrol pump attendant, but he was advised by his Doctors' to secure another job due to his haemophilia. Paul was extremely prone to injury and as such, it wasn't really an option for him to work. Following years of bleeds and bruising his joints were deformed, making it very difficult for him to mobilise.
    - 17. As a family, we involved Paul in everything we did and he loved watching his son play football, and his daughter dance. He also spent a lot of time in our garden. He tried as best he could to support our children. I remember he once dressed up as Santa Clause at the kids' school.
      - 18. Paul was a very happy family man, who adored his children. He only found it difficult and resented his situation, when he couldn't fully get involved with activities both Andrew and Michelle were doing. I remember him becoming very frustrated when he tried to play football with Andrew; he used to kick the ball with his walking stick.
        - 19. For most of our marriage, I was unable to work as Paul needed full time care. My mother was lovely and supported us financially, which is how we managed. I am not sure how else we could have put food on our table. At the time, the only support from the Government we received was Paul's invalidity pension.
          - 20. It was not until, much later in his care that a nurse called Olive Reading assisted me in obtaining attendance support. She was a lovely lady, who helped me fill in the forms and contact a social worker.

- 21.I believe Paul would have enjoyed and appreciated having a career of his own, and contributing financially to our household, but there was nothing he could do about it.
- 22. We were unable to go on many holidays; I think we managed to go on three in total, one of which was with The Haemophilia Society at a caravan park in Towyn. We were assured that Paul would have access to the medical attention he needed, as there was a haemophilia centre close by.
- 23. During the children's six-week summer holiday, they used to occupy themselves and played with one another. I would often take them to my parents' house or Chester zoo. We adapted our lives to meet Pauls' needs and the children were understanding of this. They helped their father administer his Factor products when I was busy and I believe this played an important part in the closeness of their relationship.
- 24. At age 36 or 37 my husband contracted chicken pox, which I thought was very odd, so I decided to ring our GP. Dr Barron. He was a very stern individual and didn't offer much assistance, apart from suggesting we treated Paul's skin with calamine lotion. It was quite a difficult time for both of us, as Paul was extremely uncomfortable, covered in spots and could barely swallow. He lived on rice pudding and warm soup.
- 25. The last few years of Pauls' life were extremely tough for us as a family because we saw him slowly deteriorate. He also suffered from diabetes and his body stopped responding to the insulin. I knew that his body was shutting down.
- 26. We were and are a very close family and his condition united us. He was such a loveable man and had a cheeky sense of humour. Fortunately, his Mother and siblings were always willing to pop over and help, which they also did for his brother Phillip.
- 27. In the late 80s Paul agreed to the liver biopsy study at the MRI, something I have referred to earlier in this statement. I clearly saw a change in his

behaviour; his mood was very down, and I knew something wasn't right. I also recall his skin turning yellow, but we didn't think anything of it at the time.

- 28. Before Paul passed away, we were in hospital with him and he was attached to a pacemaker. I could see that he was still breathing, but that was all. It was not long until the Doctor informed me that Paul's brain stem was dead, and I was advised to turn the pacemaker off. It was the toughest decision I have ever made, but I turned it off and we watched his heart stop beating.
  - 29. Michelle took her father's death much better than her brother; he was only 13 years old. Andrew grieved with such hatred and resentment, blaming me for what happened to his dad and snapping at me for absolutely anything. He rebelled both at home and school, making my life quite difficult at times. I know this was because he was a teenager who needed a fatherly role model, and I cannot blame him for this.
    - 30. Since Paul died, I have not kept in touch with many of his family, but I am aware that his mother feels immense guilt for passing on haemophilia to her sons. She was not aware that she carried the haemophilia gene.
    - 31. It is very sad that Paul and Phillip died from contaminated blood products.

      Phillip passed away after being infected with HIV, and since they both lived locally, we experienced the stigma associated with Phillips death.
    - 32. We live in quite a small town and the local chronicle wrote about Phillips death. It angers me that families wouldn't let their children associate themselves with Michelle and Andrew. It was well known that their uncle died of HIV, and they immediately assumed we were all positive. Ironically,

GRO-C

GRO-A

I often pointed that out to them; it was definitely a sore point at the time.

# Section 6. Treatment/Care/Support

- 33. As mentioned earlier, Paul didn't tell me much, so my knowledge of his treatment, care, and support is rather limited. Throughout most of his care at the MRI, he only received cryoprecipitate and Factor products.
- 34. He was never offered treatment for his HCV and if he was, I do not believe he agreed to have it. The hospital did mention something about Interferon, but I cannot be certain since I was not in the treatment room. I only recall this occasion, because Andrew had run off in the hospital to find his father, and he wasn't very old, maybe seven or eight years old, so I followed him. He was allowed in the treatment room with Paul and I must have overheard something along those lines.
- 35. At one stage our whole family was asked to give blood and we were tested every six months. This was immediately after Phillip had passed, but we were never informed what they were testing us for, nor given any results. I assumed it was because Phillip had HIV and that's what they tested us for
- 36. When I went back to the hospital to return the remainder of Paul's Factor products, the team of Doctors' apologised and all I wanted to know is why my husband died so young. This made me very emotional.
- 37. Paul never had any issues with accessing treatment from the dentist or any other healthcare needs. He used to be in hospital frequently to have his teeth pulled out and gums cut in order to do this, a procedure he hated.
- 38. My husband was never offered any psychological or counselling support and nor was I, or our children. It was only after he passed, that Dr Bucher

advised I saw a grievance counsellor. I believe this would have helped Andrew, but it's unlikely he would have attended in any case.

# Section 7. Financial Assistance

- 39. After Paul's death, I began to work in a care home and it was through GRO-A another haemophiliac that I came to know about the Skipton fund.

  He informed me about the fund and advised me to apply for compensation.

  I believe he had something to do with the Haemophilia Society.
  - 40.1 decided to apply in March 2011. I attached the medical documents from Paul's care at the MRI and soon found out that I was successful in my application. I could not believe this; it shocked me to the point whereby I nearly fainted. After Paul died, I didn't think about seeking compensation, I put his death to the back of my mind, and I just got on with things.
    - 41. The Skipton fund sent me a one-off payment of £20,000, and I received no monthly payments. As soon as I received a cheque in the post, I bought my house from the counsel and put some money aside for our children.
      - 42. Aside from the Skipton fund, I was not aware of any other financial support schemes.

## Section 8. Other Issues

- 43. Whilst Paul was alive, we received newsletters from the Haemophilia Society which he found informative. We also appreciated one of our last holidays at their caravan park in Towyn.
- 44.1 also organised a local bingo fundraiser to raise money and awareness of haemophilia, which members of the Haemophilia Society attended. I was delighted to have raised between £300 to £400. Our experience of the

Society is positive and I felt they helped to encourage a sense of community amongst haemophiliacs.

45.I do question why the Public Inquiry took so long to surface, and why it's taken, and is taking so long to find answers as to what happened to my Paul; I wish I knew why he had to die so young, and why he had to leave me.

### Statement of Truth

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

Signed	GRO-C	
Dated _	24.3.21	