

Witness Name: Janet Stuart

Statement No: WITN5241001

Exhibits: WITN5241002

Dated: January 2021

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JANET STUART

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I, Janet Stuart, will say as follows:-

#### **Section 1. Introduction**

1. My name is Janet Stuart. I was born on GRO-C 1972 and I live at GRO-C  
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2. My brother, Paul Christopher Mackey (born on GRO-C 1969), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII). He died as a result of Carcinoma of the Oropharynx on 21<sup>st</sup> September 2020, aged 51.
3. This witness statement has been prepared without the benefit of access to Paul's full medical records.

## **Section 2. How Affected**

4. Paul had mild Haemophilia A and was treated with FVIII concentrate twice, once during 1977 and, again, in 1983 at the Southport General Infirmary (SGI). Paul's ethos was to get on with life and to live life to the full. I remember Paul upstairs in bed (without treatment) many a time as we grew up with an elevated swollen knee or similar injury.
5. Paul was told that he was HIV positive in 1994 by Dr Woodcock at the SGI. Dr Woodcock found Paul on the ward he was admitted to after a car accident, and, he insisted on Paul having an HIV test.
6. I visited Paul at his home (in Southport where he lived with his then girlfriend) just after his discharge from hospital. I saw immediately that Paul was not himself. He was beside himself with shock and dread. He didn't tell me that he was infected with HIV, he screamed/spat it at me with rage. He really didn't know what to do with himself. It was horrendous. I stayed with Paul to try to calm him down and so that we could both think clearly. Paul was adamant that he did not want to tell our mother and I reasoned with him that it was something he couldn't keep from her. It wasn't something he could do himself and he wanted me to tell her for him.
7. Paul and I were very close. I remember a conversation I had with Paul years previously (possibly in or around 1985/1986) just after a routine haemophilia appointment. Dr Woodcock had mentioned to Paul that he could have an HIV test if he wanted one. Paul had declined. As stated, Paul had had FVIII treatment on just two occasions and thought himself highly unlikely to be infected with HIV. Paul and I had talked about HIV/AIDS as it was prevalent in the media in the 1980s. It was a fearful thing for anyone diagnosed with it for whatever reason. Paul said that if he had HIV, he wouldn't want to be told. He was adamant about that, but he felt very reassured at Dr Woodcock's apparent lack of concern about it and trusted him.

8. Paul was then appalled by the way he was told that he had HIV many years later. He didn't want to know he had HIV and was pushed into having the test whilst in hospital, having been tracked down by Dr Woodcock on the ward. Paul realised then that his clinicians had very likely already known that he was HIV positive and that the car accident and his inpatient admission to SGI was the catalyst compelling Dr Woodcock to bring it out into the open.
9. I do not believe Paul was given sufficient information or advice to enable him to understand or manage the infection. He didn't want treatment. He felt that they had 'done enough', and had lost all trust in the medical profession. He said he didn't want to be a 'guinea pig'.
10. I am uncertain as to exactly when Paul was told that he was infected with HCV as he was subsequently informed that the infection had cleared itself and was no longer active.

### **Section 3. Other Infections**

11. Paul was also advised that he had been placed at risk of vCJD. To learn of this has further added to be grief having lost him so recently.

### **Section 4. Consent**

12. Paul believed that he was tested for HIV without his consent before 1994 and without adequate and full information. Paul was likely known to be HIV positive from as early as the mid-1980s. Dr Woodcock should have had a full and frank discussion with Paul at the outset, so that Paul could make an informed choice about testing rather than the matter of fact, off the cuff, type of exchange between them in 1985/1986.

## **Section 5. Impact of the Infection**

13. Telling our mother that Paul was infected with HIV was the worst thing I have ever had to do. It was like telling her that Paul had died. It felt like a bereavement. I saw the sorrow and the guilt wash over her and settle there and there was nothing I could do except be there for her. I was no more than 22 years old at the time. Our mother had not been prewarned of any risk of infection to Paul before he had FVIII treatment (twice).

14. I was hugely impacted. From early childhood through to my late twenties when Paul settled down with his wife, Collette, I worried about him and felt responsible for him. I was always very caring, and I took on the 'looking after' role in the family. I was Paul's protective little sister. Paul had that lovely skin tone that tanned easily. At times he looked yellow in colour (possibly through hepatitis) and he was bullied but he wouldn't let me intervene. Knowing that he was infected with HIV filled me with anxiety. Knowing that we were always at risk of losing him weighed heavily on me.

15. Paul became very unwell with TB and was hospitalised after he and Collette moved to Wales and that too was another precarious and worrying time. We were afraid we might lose him.

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16. Paul's daughter, Jade, was just two years old when Paul was told of the diagnosis. His relationship with Jade's mother broke down shortly thereafter. Jade is fine now. She is amazing but the fallout from the breakdown of her parents' relationship affected her massively.

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17. Learning that he had HIV, had a huge psychological effect on Paul leaving him with very low and depressed. He had quite a philosophical ethos, but he also had a deep fear and mistrust of the medical profession and that mistrust extended to other professionals and service providers. Stigma and mistreatment through the NHS further strengthened Paul's mistrust. By way of example, to have to attend appointments for HIV treatment through a sexual health clinic is not a dignified way to treat someone infected with HIV by the NHS and was no fault of his.

18. Paul's fear and mistrust of the medical profession deterred him from seeking the help he needed for the bleed to his jaw and mouth culminating in the cancer that killed him. He was scared. I believe my sister in law, Collette, to have detailed the awful catalogue of events that led to Paul's death in her own Statement (Witness Number WITN5232001). In short, there was a lack of understanding by the clinicians at the Glan Clwyd Hospital about his condition and, what I believe was an unconscious bias on their part about him and his lifestyle. Paul was a 6ft 8inch tall man with a hippy type look. Add the HIV label to the mix and he was left vulnerable and overlooked. So much precious time was lost in dismissing Paul with inadequate haemophilia treatment and failing to refer him for the urgent specialist cancer care he needed.

19. Whilst Paul's HIV infection was not something I initially needed to share widely with anyone except my close friends, I have never felt the need to hide it. I am open and feel free to tell whoever because I feel so righteous in speaking out for Paul and what happened to him. I am immensely proud of him, his life and his achievements.

## **Section 6. Treatment/care/support**

20. Because of his entrenched fear and mistrust of the medical profession Paul went without HIV treatment until he became very ill with TB and his CD4 count was found to be at extremely low levels. None of us were offered any

psychological support or counselling. After Paul told us that he was infected with HIV that was it with no follow up contact from anyone.

21. Paul did not ask to be infected with HIV and he didn't want to know, let alone be tested and be told of the result. His peace of mind was destroyed and that was never acknowledged. The psychological impact on Paul was never recognised and addressed.

### **Section 7. Financial Assistance**

22. I am unable to comment on the financial assistance Paul had from the Trusts and Funds.

### **Section 8. Other issues**

23. My mother, Deirdre Mackey, and my niece, Jade Stone provided Witness Statements to the Inquiry (Witness Numbers WITN1686001 and WITN4112001 respectively) before Paul's cancer diagnosis and death. They have each prepared an update/addendum encompassing Paul's death and its impact on them. I refer to Exhibit **WITN5241002** being a copy of the addendum.

### **Anonymity**

24. I do not wish to remain anonymous and understand that this Statement will be disclosed for publication to the Inquiry.

### **Statement of Truth**

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

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Signed.....

Dated... 24.04.2021 .....