

Witness Name: Katherine Victoria Burt

Statement No.: WITN6392285

Exhibits: WITN6392286-7

Dated: 7 September 2023

## **INFECTED BLOOD INQUIRY**

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### **FOURTH WRITTEN STATEMENT OF KATHERINE VICTORIA BURT ON BEHALF OF THE HAEMOPHILIA SOCIETY UK**

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I provide this statement on behalf of the Haemophilia Society UK in response to the request under Rule 9 of the Inquiry Rules 2006 dated 29 June 2023.

I, Katherine Victoria Burt, will say as follows: -

#### **Section 1: Introduction**

1. My name is Katherine Victoria Burt, and I am known as Kate. I am the current Chief Executive of the Haemophilia Society ("the Society") whose registered address is 52B Borough High Street, London, SE1 1XN. My date of birth is GRO-C 1965. I have held the position of Chief Executive of the Society since 5 October 2020. All references hereafter to "the Society" are to the Haemophilia Society unless otherwise indicated. I am authorised by the Society to make this statement.
2. Prior to joining the Society in October 2020, I was an Executive Director at Leonard Cheshire, a global disability charity, leading their marketing and fundraising work. I have also worked as:
  - a. a director at Police Now, recruiting individuals to be police officers;

- b. as the chief operating officer at Greenhouse Sports, a charity working with young people in inner cities helping them to release their potential through sport; and
  - c. from 2012 to 2014, I was the chief executive of British Rowing;
  - d. as well as a number of other roles, including the Director of Business Development at The Prince's Trust.
3. This is my fourth statement to this Inquiry. My first statement to the Infected Blood Inquiry ("the Inquiry") is dated 9 August 2022 [WITN6392001] ("my first statement to the Inquiry"). My second statement to the Inquiry is dated 16 December 2022 [WITN6392268] ("my second statement to the Inquiry"). My third statement to the Inquiry is dated 6 June 2023 [WITN6392284] ("my third statement to the Inquiry"). The Society has also made a closing submission to the Inquiry on its own behalf, and on behalf of its members, to include those designated with Core Participant status in the Inquiry and represented by Eversheds Sutherland (International) LLP [SUBS0000065]. It has also made a submission on evidence in the week commencing 24 July 2023 on Compensation [SUBS0000076].

## **Section 2: Response to Criticism by Witness W0096**

4. In this statement, I address the matters that this Inquiry has requested that I respond to in the Rule 9 Request dated 29 June 2023 in relation to criticisms made by a witness with the Inquiry reference number W0096 ("Witness W0096") in their supplementary written statement to the Inquiry [WITN0096008] ("Witness W0096's supplementary statement").
5. The relevant criticism is at pages 4 to 5 (paragraphs 15 to 20) of Witness W0096's supplementary statement. Witness W0096 complains about the information she was given by the Society in 2012 about whether it is possible to "grow out" of *von Willebrand's Disease*. The relevant paragraphs in Witness W0096's supplementary statement are set out below.

*15. Between paragraph 23 and 24 of my previous written statement dated 08 March 2019, I had stated that in 2012, I was told by Doctor Orla McNulty at Belfast City Hospital, that I had grown out of my Von Willebrand's Disease and that they had made me all better. As far as I was aware, you could not grow out*

*of a condition that you are born with, and is passed through the hereditary line. If you are born with it, you die with it. This made me so cross and upset to think I may not have needed all of the blood products I had been given and how my family have been told they all have grown out of Von Willebrand's in the 1 year.*

*16. Therefore, later in 2012, I decided to get a second opinion on whether this information was true. I got in contact with the Haemophilia Society in London over the telephone. When the lady answered, the name of whom I cannot recall, I recounted the information that I had previously been told about my Von Willebrand's Disease. She stated something along the lines of "as far as I am aware, I did not know this was possible, where did you get this information from?" I replied stating that I had received this information from Doctor Orla McNulty at Belfast City Hospital. After this, she placed me on hold to get a second opinion from her superior.*

*17. I was on hold for ten minutes. When she returned, she stated that she was in fact mistaken, and what I had been told was true. It is possible to grow out of your Von Willebrand's Disease.*

*18. After this, I had an appointment with Doctor Morgan my Gynaecologist at Antrim Area Hospital, Bush Road, Antrim, BT41 2RL. I had previously been told that I needed to undergo a hysterectomy. However, due to my Von Willebrand's, I was not able to undergo this operation due to the risks involved. He had told me that I had a fifty percent chance of dying on the table, which was too great a risk for me to take.*

*19. When I then told him what Doctor Orla McNulty and the Haemophilia Society had told me, he laughed. He said you cannot grow out of Von Willebrand's Disease. At a later appointment he chuckled when he read a confirmation he had received in writing from Doctor Gary Benson to that effect. Again, this has already been submitted. (See Exhibit WITN0096005) I have still not had the operation to this day, and Von Willebrand's has not been taken off my medical records.*

*20. Any Doctor I have told agreed that it was not possible to grow out of a hereditary condition. Are Dr Gary Benson and the Haemophilia Society mistaken? or are they covering something up? I cannot pass comment to that*

*effect but the question eats away at me. How did my family all grow out of Von Willebrand's in the same year.*

6. At paragraph 16 of Witness W0096's supplementary statement, they state that they cannot recall who they spoke with from the Society in 2012 when they received the information complained of. Without this information, the Society is unable to further investigate and respond to Witness W0096's criticism with specificity. Although the picture that Witness W0096 paints is incomplete, the Society wishes to acknowledge W0096's criticism and make a number of observations, which are set out below.
7. It is fairly well-known that levels of *von Willebrand's Disease* can change throughout a patient's life.<sup>1</sup> However, the message reported to have been conveyed by the representative of the Society that you can "*grow out*" of *von Willebrand's Disease* (as recounted by Witness W0096 in their supplementary statement) was factually inaccurate. It is true that a person's levels of *von Willebrand's Disease* can change and they can, in that sense, "*grow out*" of the symptomatic phase, becoming asymptomatic. However, it is also true that a person cannot "*grow out*" of *von Willebrand's Disease* genetically (even if they are asymptomatic). A person will always have *von Willebrand's Disease* in their genes. If this nuanced level of explanation was not given to Witness W0096 at the time, I apologise. When the Society responds to queries from members, it is common practice to use lay language, but accuracy also needs to be maintained.
8. As mentioned in paragraph 172 of my first statement to the Inquiry [WITN6392001], it is not the Society's role to give medical advice to its members. It is the Society's policy to suggest that a person speak with a haemophilia haematologist about their diagnosis. This policy would always apply and particularly in circumstances where they are seeking advice about something like *von Willebrand's Disease*, which is an extremely complex disease.
9. In circumstances where unfortunately, Witness W0096 cannot recall who they spoke to from the Society at the relevant time, the Society cannot do any more in terms of investigation of the criticism. Therefore, all I can do is offer an apology for the hurt the witness clearly feels and for any uncertainty caused. Witness W0096's supplementary statement has caused the Society to reflect on the importance of conveying information

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<sup>1</sup> For example, see further Mouhamed Yazan Abou-Ismaïl, Gbolahan O. Ogunbayo and Peter A. Kouides, "Outgrowing" the Laboratory Diagnosis of Type 1 Von Willebrand's Disease: A Two Decade Study', *Blood* (2016) Volume 128, Issue 22, page 871 [WITN6392286]; and Michael Laffan, 'Can you grow out of von Willebrand disease?' *Haemophilia* (2017) Volume 23, Issue 6, page 807 [WITN6392287].

in a clear and precise way and we take this as a point of learning for future communication with our members.

### **Section 3: Additional point re Witness W0096's Supplementary Statement**

10. I also wish to make note of another point raised in Witness W0096's supplementary statement.. At paragraph 2 of their supplementary statement, Witness W0096 refers to a *"database run by the Haemophilia Society"* and explains *"[t]his database contains details of all blood products administered under the National Health Service ("NHS") from 1992 onwards and includes details of the recipient."* The Society does not run this database. As can be seen from the letterhead on the exhibit to Witness W0096's supplementary statement [WITN0096009], the National Haemophilia Database is run by the U.K.H.C.D.O.
11. The Society notes that at paragraph 6 of their supplementary statement, Witness W0096 states, *"[i]f it was not for the Haemophilia Society database shedding new light on the point of my infection, I would still to this day be unsure of the likely true cause of my infection, despite the letter from Dr Mayne. The database provided corroboration"*. The Society cannot take credit for providing this corroboration.

### **Section 4: Conclusion**

12. As noted in the Society's closing submission [SUBS0000065], the Society knows that some of its members are angry and disappointed by actions taken by the Society in the past. Some felt unsupported and believe more should have been done to help them. I and the Society of today, with the full support of the Board, have taken on board the contents of all this evidence, including the statement to which I am responding. As I noted in my second statement to the Inquiry (which addressed criticisms made by Witnesses W1122, W5739, W1055, W1056, W1210, W1791, W3988, W4120 and W3261), I recognise that there is hurt and an enduring feeling by some that the Society let them down. I would like those individuals, including Witness W0096 and all reading this statement, to know that the Society is assisting the Inquiry in every way it can. It wishes to face its past so that it can do better in the future. The Inquiry provides an opportunity for healing. The Society has done what it can to respond to Witness W0096's criticism but unfortunately, it cannot do much more without knowing who Witness W0096 believes they spoke with in relation to their

diagnosis with *von Willebrand's Disease*. As noted above, all I can do is offer an apology for the hurt the witness clearly feels and for any uncertainty caused.

**Statement of Truth**

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

Signed GRO-C \_\_\_\_\_

Dated 7 September 2023

**Table of exhibits:**

Date	Notes/ Description	Exhibit number
2 December 2016	Mouhamed Yazan Abou-Ismaïl, Gbolahan O. Ogunbayo and Peter A. Kouides, "Outgrowing" the Laboratory Diagnosis of Type 1 Von Willebrand's Disease: A Two Decade Study', <i>Blood</i> (2016) Volume 128, Issue 22, page 871	WITN6392286
17 November 2017	Michael Laffan, 'Can you grow out of von Willebrand disease?' <i>Haemophilia</i> (2017) Volume 23, Issue 6, page 807	WITN6392287