Witness Name: Brendan Brown

Statement No.: WITN4496017

Exhibits: WITN4496018 - WITN4496020

Dated: 26 August 2021

#### INFECTED BLOOD INQUIRY

# FOURTH WRITTEN STATEMENT OF BRENDAN BROWN ON BEHALF OF NHSBSA

I, Brendan Brown, Director of Citizen Services of National Health Service Business Services Authority ("NHSBSA"), will say as follows: -

1. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 July 2021. As with my first three statements, this statement is based on information available to the NHSBSA from its records of the England Infected Blood Support Scheme ("EIBSS") and the knowledge of members of the EIBSS team. I have made clear where the information is from my own personal knowledge.

## Section 1: Introduction

2. My full name is Brendan Craig McMahon-Brown (known as Brendan Brown) and I am the Director of Citizen Services at NHSBSA, based at Stella House, Goldcrest Way, Newburn Riverside, Newcastle Upon Tyne NE15 8NY. Details of my professional background and career are set out in my first statement.

#### Section 2: Response to criticisms of W1589

3. My attention has been drawn to criticism made by witness W1589, in her second written statement to the Inquiry.

- 4. At paragraph 16(c) of that statement, W1589 refers to an anonymous witness and campaigner known as "Frankie," who she states "continues to pursue the inequality and discrimination in lump sum payments to people with HIV with EIBSS and the matter is ongoing." She refers to the payment made by EIBSS to all beneficiaries with a Hepatitis C infection whereas EIBSS paid different amounts to beneficiaries with HIV infection depending on the circumstances (e.g. including age and marital status).
- 5. On behalf of EIBSS, I am sorry to hear that anyone holds a belief discrimination exists within the payment scheme we administer on behalf of the Department of Health and Social Care ("DHSC").
- 6. The lump sum HIV payment criteria is defined in the EIBSS specification, which was provided to EIBSS by DHSC. As set out in my earlier evidence to the Inquiry, NHSBSA administers EIBSS on direction from the Secretary of State for Health and Social Care, in compliance with this specification. This means NHSBSA has no power to act outside of the EIBSS specification and what it has been directed to do. If a beneficiary considered that the payments set out within the specification were discriminatory, EIBSS could pass that feedback on to DHSC to consider. A beneficiary could also raise their views through other routes, such as directly to DHSC or via the All-Party Parliamentary Group on Haemophilia and Contaminated Blood. However, only DHSC could amend the defined payment amounts to which NHSBSA administers in accordance with the EIBSS' specification.
- 7. On 25 March 2021, the Paymaster General provided an update on parity of financial support across the infected blood support schemes administered within each of the four nations. The announcement is discussed in more detail in my first statement at paragraphs 259 260 and 310. It is possible that the payment changes resulting from this announcement may have addressed the concerns raised by Frankie, as the changes planned are aimed at bringing greater parity between the different schemes operated throughout the UK. NHSBSA is fully in support of these changes, as they will deliver very positive additional support for EIBSS scheme members. In particular, the lump sum

payment paid to a beneficiary in the scheme with HIV will increase from "up to a maximum of £80,500" in England to an *automatic* £80,500 payment. This change introduces a HIV lump sum standard rate that replaces the previous variable lump sum HIV rates. The change is applicable to all current scheme members, so some beneficiaries will now have the lower amounts they were previously paid topped up so that all have received £80,500.

- 8. At paragraph 16(d), the witness states that a discretionary payment is available either toward funeral costs when a beneficiary has died (which I confirm is available regardless of the type of infection) or a prepayment plan when a beneficiary has received the Hepatitis Stage 2 payment. W1589 states that no such prepayment plan is available for someone with HIV. On behalf of EIBSS, I am able to confirm that the entitlement to a prepayment plan for a Hepatitis C stage 2 infected beneficiary is based on medical advice that a beneficiary at this stage of EIBSS support is likely to have a terminal diagnosis. This process has therefore been put in place to support beneficiaries who wish to plan for their funeral, due to their increased likelihood to pass away in the near future. EIBSS is able to apply administrative discretion for discretionary support payments, such as towards prepaid funeral plans. Discretion could be applied where a HIV beneficiary has received a terminal diagnosis and provided supporting information with their application. I have asked the EIBSS team to look into this issue further, so that the position is clearer and consistent for all beneficiaries.
- 9. At paragraph 42 of her second written statement, W1589 states that she was asked to complete an NHS Low Income Scheme ("LIS") form for reimbursement of hospital travel for a consultation relating to HIV infection in late 2018. She explains in her statement that, in 2020, "On asking, I was told the policy had changed so that there was now no requirement to fill out a form. I was told the policy was reviewed in July 2018. Therefore, in late 2018, I appear to have been told something that was false and consequently did not claim for travel to and from hospital appointments for HIV and co-morbidity complications from late 2018."

- 10. To explain, when NHSBSA became administrators of EIBSS, we were asked to undertake a review of the discretionary support provided by the previous Alliance House Organisation ("AHO") schemes, as set out in more detail in my first witness statement. EIBSS provided a draft report to DHSC in April 2018 and a new policy for discretionary payments was implemented in July 2018. DHSC instructed NHSBSA to amend their administrative support based on this report and from this point EIBSS worked to a single discretionary support framework. One of the newly agreed rules about discretionary support was that beneficiaries had to complete a LIS application to be awarded either a HC2 or HC3 certificate (for full/partial help towards health costs), as this was an existing form of support for NHS treatment charges and associated travel for treatment.
- 11. Subsequently, following feedback received at the late November 2018 EIBSS focus group and a letter from the Contaminated Blood Campaign ("CBC") relating to this scheme change (Exhibit WITN4496019), EIBSS formally put forward concerns raised around the LIS application process by beneficiaries to DHSC for consideration in December 2018. Broadly, the concerns raised were that completing a very long form to receive support for hospital travel costs for treatment caused by their infection was unfair and could lead to some beneficiaries not attending appointments. Based on the information provided by EIBSS to DHSC, DHSC considered the options, which resulted in an easing of the policy on having to complete an LIS application in order to receive hospital travel costs. EIBSS contacted all beneficiaries (via their preferred contact preference letter/email/telephone) in March 2019. I attach a template letter relating to this LIS update as Exhibit WITN4496018. In this update, more information about LIS and the added benefits that this process may bring was provided, along with confirmation that we would continue to accept discretionary support applications for refunds of eligible NHS treatment costs under EIBSS too. As part of the communication, NHSBSA proposed that all EIBSS beneficiaries should be automatically registered with LIS so that they were all entitled to receive full help with health costs without an application having to be made by individual beneficiaries. Unfortunately, this proposal has not been progressed as it required a significant regulatory change within another DHSC policy area. The process of either applying to LIS or submitting

- a completed refund application form to EIBSS remains in place to date.
- 12. At paragraph 43 of her second statement, W1589 states "Furthermore, in 2018 I was told I could claim for a prepaid funeral grant. Then I was told by another member of staff that I could not as I was not "Hep C Stage 2". I challenged this policy and was told it was because HIV is a manageable condition." It is not clear from her statement but I have assumed that she is referring to information she received from two different members of EIBSS staff. She also states that "I was told that it was common knowledge on the internet that HIV was manageable. I challenged the use of the internet to form policy as it is an inappropriate source of information."
- 13.1 confirm that EIBSS has independent medical assessors involved with the scheme who assess initial applications to the scheme, one of whom must be a HIV specialist medical assessor. Any HIV advice is sought from this specialist, rather than simply through an internet search. Although the original advice as to manageability of HIV was provided by a previous HIV specialist EIBSS medical assessor, my team has asked the current HIV specialist EIBSS medical assessor for advice (Exhibit WITN4496020). This HIV specialist medical assessor agrees that, although there is no current cure, the advancements of antiretroviral medications available for those infected with HIV enable most people with the virus to live a long and healthy life. Due to this, HIV is considered to be a chronic manageable condition. The HIV specialist medical assessor has confirmed that the current life expectancy for someone with HIV is comparable to that of the general population in the UK. The increase in both longevity and overall health is mainly due to the development of antiretroviral drugs capable of suppressing HIV viral replication resulting in preservation of the immune system. However, for the avoidance of doubt, the HIV specialist medical assessor does agree that people with HIV may still have a number of health problems and some may be unable to take some antiretrovirals due to side effects or viral resistance. The HIV specialist medical assessor notes that living with a chronic illness may also produce additional stresses and reduced wellness and well-being and infection with HIV remains stigmatised.

14. EIBSS is able to apply administrative discretion for discretionary support payments (as stated in paragraph 3.2.16 of the EIBSS specification previously mentioned and which has already been provided to the Inquiry), such as towards prepaid funeral plans. As set out in paragraph 44 of W1589's second statement, EIBSS have previously advised in response to a Freedom of Information Act 2000 request that EIBSS has provided support towards prepayment plans for funerals to a small number of beneficiaries who are receiving different categories of support from the scheme, including those infected with HIV. Each case is unique and the numbers are at such a low level that EIBSS is unable to provide more detailed reasons as to why the discretion was applied in those cases. NHSBSA therefore disputes any suggestion in W1589's statement that a Hepatitis C Stage 1 beneficiary only received a prepaid funeral plan as he had been given false information about his eligibility. As above, I have asked the EIBSS team to look into this issue of prepayment funeral plans further, so that the position is clearer and consistent for all beneficiaries.

#### Section 3: Other issues

- 15. I would like to take this opportunity to address several other points mentioned within W1589's second written statement, which I have done below.
- 16. In relation to her paragraph 9c, I confirm that the purpose of the EIBSS focus groups is to enable the NHSBSA team responsible for EIBSS to meet with beneficiaries who receive support from the EIBSS scheme it administers and to receive feedback on EIBSS from those beneficiaries. All beneficiaries, regardless of their infection, have equal opportunity to provide feedback, as every beneficiary has a unique insight, which may not only assist them but others too. EIBSS is saddened to hear that W1589 believes "disability discrimination" has taken place at an EIBSS meeting. I will instruct the EIBSS support team to be vigilant for anything of this nature at future focus groups meetings and to challenge it if so. W1589 also mentions verbal abuse at EIBSS meetings in paragraph 16(a) of her statement. I am saddened to hear of any

mention of verbal abuse at an EIBSS meeting. If further detail on this point could be provided, I will have the matter investigated.

- 17. At paragraph 9d, W1589 refers to the minority status of HIV within the wider contaminated blood community. EIBSS recognises that there are fewer HIV beneficiaries supported by the scheme but this does not mean that they receive a lesser service or that their feedback is not given equal consideration to that of any Hepatitis C beneficiary. EIBSS provides a professional service to all beneficiaries regardless of the type of infection. As explained above and in my third witness statement, EIBSS' general approach is to treat all beneficiaries equally in terms of access to and attendance at focus groups. However, EIBSS will arrange additional focus groups for a certain group if there is a collective agreement by beneficiaries to do so. Indeed, in November 2020, an additional online focus group for HIV infected beneficiaries only was held to address specific HIV related feedback about the scheme, which was attended by a Terence Higgins Trust representative, as they are also a beneficiary of the scheme. All beneficiaries can also provide their feedback directly to the EIBSS team by telephone and/or via email at any time too.
- 18. In response to W1589's paragraph 16(f), I would like to reiterate that NHSBSA administers EIBSS, on behalf of DHSC. If DHSC choose to amend the scheme rules, EIBSS will act upon the revised instruction and administer any changes. I confirm that the EIBSS section of the NHSBSA website (at <a href="https://www.nhsbsa.nhs.uk/financial-and-support-services">https://www.nhsbsa.nhs.uk/financial-and-support-services</a>) does signpost to support organisations for HIV as it refers to the Terence Higgins Trust, Positively UK and the National AIDS Trust.

## **Statement of Truth**

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



Dated 26 August 2021

# Table of exhibits:

Exhibit number	Date	Notes/ Description
WITN4496018	Undated	NHSBSA template letter relating to Low Income Scheme ("LIS")
WITN4496019	Undated	"CBC Statement of Deep Concern re Changes to the EIBSS Discretionary Support Scheme for Those Most Seriously ill and in Need of Medical Support", by the Contaminated Blood Campaign
WITN4496020	28 July 2021	"HIV is a Chronic Manageable Disease" – advice by Dr. Catherine C. Smith