Witness Name: Clair Walton
Statement No. WITN1589023
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INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF CLAIR WALTON

Introduction

1. My name is Clair Walton, and I make this third written statement in order to add greater detail to and update my second written statement dated April 2020. I make this statement of my own initiative and have not received any further request from the Inquiry pursuant to Rule 9 of the Inquiry Rules 2006.

2. I explained in my first written statement how my husband, Bryan Walton (deceased), became infected with HIV and Hepatitis C from contaminated blood products. I also explained the circumstances in which I became infected with HIV myself.

3. The purpose of this statement is to add further information regarding events that have occurred since my second statement was filed with the Inquiry. I also want to discuss how the All Party Parliamentary Group on Haemophilia's ("the APPG") 2015/16 consultation came about and how it led to current infected blood support schemes.

4. Except where I indicate to the contrary, the facts of the matters set out in this witness statement are within my own knowledge and are true. Where the facts are not within my own knowledge, I have identified the source of my information and believe them to be true to the best of my knowledge, information, and belief.

5. I use the phrase "HIV positive women" throughout this statement as a shorthand term for women who have been infected with HIV as a result of their relationships with men who suffered from bleeding disorders and who came to be infected with HIV through

the use of contaminated blood products. For the avoidance of all doubt, I do not refer to HIV positive women in general.

Campaigning activities and meetings with the APPG

5. As referred to in my second written statement, I set up an informal group called Positive Women (HIV via Factor 8) (“Positive Women”) with a fellow campaigner (known to the Inquiry by the alias “**GRO-A**”, in around 2017. The aim was to provide support, and to campaign for women who, like myself, were infected by their bleeding disorder suffering partners and who have been dealing with the repercussions ever since the 1980s.

6. The full aims and objectives of Positive Women were set out in my previous written statement, but one of the concerns was the discrimination faced by women in the community, particularly surrounding payments provided by the financial support schemes and the disparity within the existing schemes.

7. One of our purposes was to campaign for compensation to be assessed on an individual basis. In addition, we were campaigning to combat the marginalisation of HIV mono-infection in the wider infected blood community, due to the minority representation of HIV at EIBSS and the All-Party Parliamentary Group on Haemophilia and Contaminated Blood (APPG) meetings which I had experienced throughout my campaigning.

8. We want to dispel the myth that HIV is cured by taking a daily pill, or that it is a manageable condition. There is no widespread cure for HIV. Whilst it may be manageable for some people by taking a daily pill, those of us who have been living with HIV for decades have a very different experience from those who are newly diagnosed and particularly, those who did not have to undergo the first, primitive attempts to treat HIV. Given the distinct lack of support or advocacy for HIV positive women, I felt it was crucial for our voices to be heard. Therefore, we campaign for research on the current and long-term health needs for those of us living with HIV, as well as specific research on the effects of HIV on our bodies, as women. As infected wives and partners of haemophiliacs, we do not have access to the specialist care provided by many haemophilia centres.

9. Although I was already meeting with the APPG long before 2017, I also met with the APPG through Positive Women which meant that we had a place at the table as a campaign group.

10. I met with the APPG to amplify the voice of those living with HIV as a result of infected blood products, which I felt, had become lost to an extent within the greater numbers of people who were mono-infected with HCV.

11. I raised concerns through my MP, Nadim Zahawi, from 2013 when I first approached him. The concerns I raised related to (but were not limited to):

- Management of the Macfarlane Trust ("MFT");
- The loans the MFT gave to beneficiaries instead of grants;
- Legal charges the MFT had placed on homes of beneficiaries (something I experienced myself and refer to in detail in my first written statement);
- Discrimination against women by the new HIV schemes as infected widows were not recognised as both 'bereaved' and 'infected' by the MFT (and later EIBSS); and
- The voice of those suffering HIV being marginalised.

12. My main concern was regarding the MFT support scheme, and particularly the inequality in support for women who had become infected with HIV through their partners. We were referred to as 'infected intimates' by the MFT (and then later EIBSS), which I consider an offensive term; it is pejorative and belittles us by defining us through our partners - it is indicative of the second-class way in which we were routinely treated.

13. I believe that the use of the term "infected intimates" directly led to less favourable financial treatment from the MFT – if categories had to be used, then there is no reason why would should not have simply been set alongside our partners, as primary beneficiaries.

14. MFT eventually stopped using the term 'infected intimates' and we became primary beneficiaries in our own right alongside infected haemophiliacs. We then discovered that, for no apparent reason, the term was also used by EIBSS several years later when they came into operation in 2017.

15. This is just one example of why we continue to campaign for the very small voice of HIV positive women, because nobody is advocating for us. I had hoped that the

Terrance Higgins Trust would help us do this going forwards but, unfortunately, this did not transpire.

The APPG survey leading to new schemes

16. In 2014, I was involved in a discussion led by Alistair Burt MP with one of his constituents, Nadhim Zahawi MP, and one other co-infected individual.

17. This was an informal discussion in a café at the House of Commons after a debate regarding contaminated blood products (which was then centred around haemophiliacs).

18. Alistair suggested a survey of people's experience of the schemes, and a reform because of concerns that had been raised by infected and affected individuals about the operation of the various Trusts and schemes at the time. He wanted to hear of everybody's experience in the wider community, including the 'quieter' members who were not in contact with their MPs. This then led to the APPG consultation.

19. The APPG undertook an inquiry into the support for those affected by the contaminated blood issue in 2015. The results revealed inadequacies with the existing support arrangement, and it was recommended that the Department of Health should carry out a holistic independent assessment of the support necessary, and review whether the five schemes ought to be combined to allow easier access for beneficiaries.

20. One of the problems with the APPG consultation was that the small group of people within the MFT who were HIV co-infected were pooled into a much wider group of people who had been infected with HCV whether through the use of blood products or whole blood transfusions – in my opinion, this had the effect of diluting the voice of the MFT beneficiaries.

22. As a community of people who have HIV, we should have been consulted and our views evaluated alongside those who are co-infected and those who have hepatitis and are mono infected. Instead, the views of all beneficiaries of all of the trusts and schemes were merged, and it was not apparent that any weighting was given. For this reason, I felt that the results of the consultation were not representative of the views and opinions of the MFT community.

23. If the results of the consultation indicated that a "majority of people" opted for something, I queried who that majority was. As a woman infected with HIV, my voice was not being heard, and there are already so few of us speaking out.

24. I consider that the APPG consultation was a lost opportunity which resulted in the silencing of the MFT beneficiaries.

25. Following on from the survey, in January 2016 there was a consultation on the reform of the ex-gratia payment schemes for those infected with HIV and/or Hepatitis C. In my opinion, the consequences of the Department of Health consultation were disastrous because the voice of the MFT beneficiaries became lost even further within the wider blood community.

26. In July 2016, the Government announced their response to the January 2016 consultation and announced details of a reformed English support scheme for those affected by contaminated blood.

27. While the new English scheme could be said to be an improvement on the proposals in the January consultation, it still fell short as, despite assurances to the contrary, some beneficiaries were worse off. Liz Carroll, the Chief Executive of the Haemophilia Society at the time, said the community would welcome the replacement of the Alliance House organisations with a single scheme administrator.

28. I am not sure on what basis Liz Carroll said this. I think Liz could only have been referring to the entire infected haemophilia community incorporating the much larger number of people mono-infected with HCV.

29. Whilst I never saw eye to eye with the MFT, it being consumed by EIBSS meant that the HIV specific voice was diluted, if not lost entirely.

<u>Terrance Higgins Trust: developments since my last statement in April 2020</u>

30. Since the Terrance Higgins Trust ("THT") took over the remaining assets from the MFT when they shut down to continue providing support for beneficiaries, I have tried to foster engagement with THT as an individual and through Positive Women. I saw THT as a new opportunity for our voices to be heard, rather than a threat.

31. As mentioned in my previous statement, a new relationship had been formed with THT, and the intent was to look forward.

32. In 2018, THT launched a three-year project called 'Amplifying our user voice', following a £1.1 million investment from the National Lottery Community Fund. The purpose of the project was to revolutionise beneficiary involvement in a meaningful way so to bring new approaches to adapt how THT worked to ensure it was meeting the needs of beneficiaries. The objectives of the project were set out in a press release by THT.

33. From the outset, THT promised that user voices would be heard, and this would in turn, guide THT on how residual MFT monies would be utilised to address the needs of its beneficiaries.

34. To meet this objective, I was identified by the lottery project THT User Involvement Team to help change how THT worked. I was asked to attend training in 2020 and to work with THT to create co-production principles.

35. A User Group specific for MFT beneficiaries was set up 2020.

36. I felt as though GRO-A and I were constantly educating THT on matters they should have been already aware of, such as the differences between blood transfusion and blood products, or how the MFT beneficiaries were distinct from the wider contaminated blood community. We were constantly helping them by providing our knowledge and we were effectively their consultants, although not recognised as such. Instead of working with us, THT ultimately excluded us from their use of the former MFT funds.

37. I was involved in a small team within the THT User Involvement Team that developed an online training module for the wider THT on user involvement/ co-production. The co-production principles were simple principles centred around working with people and sharing responsibility: the main premise was that you work with people to support people. While working with THT, my aim was to encourage them to adopt principles of co-production. I do not believe they upheld this with MFT beneficiaries, however.

38. For example, THT had never historically supported the contaminated blood cause. I had asked them to take a stand on the issue, and a contaminated blood campaign was produced and presented to us; however, this was done without any consultation or input, and it fell short.

39. I also tried to develop the HIV voice within EIBSS and asked THT to set up a HIV specific focus group meeting with EIBSS, which EIBSS had not historically done. We had a meeting with EIBSS and THT in late 2020 which GRO-A and I attended. We explained that we needed support and research surrounding the comorbidities and ongoing health concerns for the HIV group as a result of taking various drugs for decades, and the ongoing mental health impact.

40. THT agreed to meet again with EIBSS but never informed us of the outcome. Later, through the Freedom of Information Act, I discovered that in a subsequent meeting THT had with EIBSS, the THT member of staff asked for mattresses for the coinfected because they have night sweats. Nothing surrounding the bigger picture of HIV had been presented; there was no mention of a lump sum that we were trying to advocate for. We wanted support and advocacy so that our voice was not watered down, but THT failed to consider what was happening to us as HIV positive women, or the evidence they should be collecting on our behalf for an assessment of our future needs.

41. Through my training with the User Involvement Team at THT, I had tried to gain support from THT so they would help us to self-advocate. Despite my attempts to improve the relationship we had and push for co-production principles, THT kept us at a distance, and we were not consulted when they were having meetings without us.

42. For example, THT met with politicians without our knowledge or any consultation with the former MFT beneficiaries. THT had met with Diana Johnson and the APPG without informing or including us in that discussion. They attended at least one APPG meeting that I know of and did not tell us the meetings were going on, or even what had been said. This is even though we were told that they would not meet with officials without including us, circling back to the co-production principles. It was all just words, and they did not demonstrate the core principles.

43. THT's excuse for not contacting the MFT beneficiaries when they took over the MFT funds was that they did not have our data due to data protection. I do not think this is an adequate excuse.

44. I do not understand how THT could have accepted the MFT's residual funds without knowing who the beneficiaries were or considering how they might be contacted; there is no possible way that THT could employ the residual funds for the benefit of the

former MFT beneficiaries without knowing who they were or having any way to contact them.

45. Instead of contacting beneficiaries, THT took the assets and made no effort to find out who they were. The only reason some of us had been contacted by THT was because they had a legal requirement to write to us as they had acquired charges over our properties (which I referred to in in detail in my previous evidence). This concerns me greatly; had THT not acquired the charge over my house, I doubt they would have written to me at all as they would not have had my contact details.

46. I digress slightly here to note that when the registered charges at the Land Registry over MFT beneficiaries' properties, on my property and at least one other that I know of, under "Lender" it was changed to state "The Terrance Higgins Trust" – this represents a terrible breach of confidentiality – MFT was a relatively obscure organisation out of the awareness of the majority of people; The Terrance Higgins Trust is widely known as a HIV charity and the amendments to the charges effectively identified us as HIV infected.

47. By way of example of the complete lack of contact between THT and beneficiaries, I acquired a letter dated 23 July 2021 from Ian Green, CEO of THT [**WITN1589024**]. It is a response to Sir Robert Francis QC regarding the infected blood compensation study. This letter was not sent to me as a beneficiary, so I would not have known of its existence had someone else not drawn my attention to it. In the letter, Ian Green is keen to mention in his fifth paragraph, the wider community who are not infected; however, the infected wives and partners are simply an afterthought at the end of the letter. Even after all the time spent with THT to raise awareness, we are just referred to in one line at the very bottom; moreover, I simply cannot understand why this was not sent to me by THT given that by their account, I am one of the few beneficiaries who they have identified.

48. The User Group I was involved in was eventually shut down by THT. Prior to this, I had lost all confidence in THT's abilities to act in our best interests. In the first User Group, there were only four of us in attendance, and I questioned who else had been invited. I got the impression they were not publicising it widely enough or not communicating it to everyone who should have been aware. The point of the User Group was to hear the voice of beneficiaries, but there was only a handful of us there. A new User Group has since been set up, but I am no longer involved given my doubts

over its effectiveness. My ongoing concern is what THT is doing in our name without consulting us.

49. I do not consider that THT is fit to manage the MFT residual funds. The objectives of the majority of THT beneficiaries are to minimise the stigma which remains around HIV. They do this through initiatives such as a "U=U" campaign. Whilst we understand why they do that, those infected through contaminated blood products are more focused on the consequences of living with HIV in the long term, the co-morbidities that come with it, and the fact that living with HIV is not as simple as taking a pill every day and enjoying a normal life. I think that this difference in approach points to a fundamental and irreconcilable conflict of interest between THT and the former MFT beneficiaries.

50. We were willing to help and work with THT. Instead, they shut us out and did what they wanted without involving us. I simply cannot understand the logic or motivation for THT's actions – if they are trying to burn through the residual funds then that is one thing but to burn through it with ham-fisted attempts at advocacy over issues that they have no detailed knowledge of runs contrary to the duty of care that they have adopted.

51. Historically, my attempts to engage with The Haemophilia Society were met with little to no support. I had attempted to communicate and paid for my travel to London to meet with them, but the conversations led to empty promises. However, I am currently in conversations with the new Chief Executive, Kate Burt, who is very supportive, and I hope we can continue a positive dialogue for a better a future.

52. The Haemophilia Society need to embrace and support us. Historically, they have not been helpful, and it was only through sheer determination and campaigning either individually or through Positive Women that there had ever been any action by the Society.

53. I was married to a haemophiliac who then died through contaminated blood products. When he was in hospital, there was a support network next door to the haemophilia unit. I have no support and no network. This is what I thought THT could understand and provide when I was working with them.

54. Our specific needs as HIV positive women from the MFT is very different from the rest of the wider HIV community.

55. I received an email from THT titled “growing older with HIV” which typically demonstrates how those of us living with the condition for decades are overlooked. The opening paragraph states:

> *“…People living with HIV can expect to live long healthy lives…”*

56. Whilst this may be the case for someone that is diagnosed recently, for those who were diagnosed in the 70s/ 80s, this is certainly not true. We have been taking medication for decades which has an adverse effect on our health, and I refer to this in my previous evidence.

57. In the same email, there is no regard for women with HIV, the long-term effects of living with the condition for decades, or the need for specific research.

58. In March 2021, the Daily Mail published an article on HIV positive women following the popularity of Russel T Davies’ drama ‘It’s A Sin’. **GRO-A** and I were deeply disappointed that we had not been approached by THT to speak to the media for our voice to be heard, because none of the women featured in that article had been diagnosed in the 1980s. The impact of ‘It’s a Sin’ provided an opportunity for the silenced of the 1980s to be heard. We were there living through the pain and suffering, caring for our partners, becoming widows, and dealing with our own diagnosis, amid stigma and discrimination.

59. Following this, I emailed Ian Green requesting a meeting to address the fact that the User Group was not fit for purpose. My concern was a lack of beneficiary involvement in the development of THT, and the failure to uphold the core principles which THT agreed to; valuing all participants, developing networks of mutual support, doing what matters for all people, and sharing power and responsibility. I stressed that that a united front was needed so that there was a voice, backed by evidence, on the impact of contaminated blood products for everyone in our community.

60. Having fostered a positive working relationship with the Chief Executive of The Haemophilia Society, a letter was sent to Ian Green on 20 October 2021 which I co-signed [**WITN1589025**]. The purpose of the letter was to highlight former MFT beneficiaries’ concern at the way in which THT were handling the residual MFT funds. Given the various shortcomings in their approach over the years, the letter expressed a clear desire for THT to cease representing MFT beneficiaries, and to release remaining funds so that they could be satisfactorily administered.

61. Whilst Ian Green accepted that THT could have done more in the past, he suggested that this stemmed from the mistaken belief that those impacted by contaminated blood products did not want to be associated with THT, due to their association with the LGBT community [**WITN1589026**]. The inference from this assertion that MFT beneficiaries did not want support from THT because they were supposedly homophobic generated further mistrust and emphasises how, despite our attempts to work with and educate, THT still fail to understand and recognise us.

62. The offence caused by the allegation is conveyed in The Haemophilia Society's response of 21 February 2022 [**WITN1589027**]. It was also requested that audited accounts be provided so beneficiaries could ascertain how remaining MFT funds could be utilised in a meaningful way. As is clear from the correspondence, the sentiment that beneficiaries wish to cut ties with THT remains.

63. Ian Green's response to this was sent on 24 February 2022 expressing a desire to move forwards with the community, it is important to note that THT had the full support of Positive Women who attempted to educate and work with them over the years. However, THT have not assisted our community, and we do not want THT to be responsible for the remaining funds going forwards. At its simplest, many of the MFT beneficiaries found the MFT abusive in the sense that you felt they had a control over your life and how you ran it – we do not want the THT to carry on this system of re-abuse.

64. On 6 April 2022, a meeting took place between most of the signatories to the letter of 20 October 2021 and THT which I attended. The aim of the meeting was to attempt to find a way forward and, for my part at least, gain a better understanding of what THT were doing with the residual MFT funds and how they planned to spend the remaining balance. I was also keen to understand the basis upon which THT claimed that they were consulting widely with the former MFT registrants.

65. I found the meeting hostile and I found THT generally evasive; I came away from the meeting with no greater understanding of how the residual funds were being spent or how THT proposed to improve beneficiary engagement.

66. As a result, **GRO-A** and I, on behalf of Positive Women, issued a statement [**WITN1589028]** setting out that THT did not speak for us and that we would have no further engagement with them. One of my hopes in making this supplemental

statement, is that it will support the making of a recommendation by the Inquiry that THT surrender what remains of the residual funds; as is noted in the statement from Positive Women, I believe that THT have a fundamental conflict of interest in attempting to advocate on behalf of the former MFT registrants.

Discrepancies in the compensation scheme

64. I received an update from EIBSS responding to queries I had about the schemes following Rt Hon Penny Mordaunt's announcement in March on the update on parity of financial support. I emailed EIBSS on 6 May 2021 asking for an update and whether I needed to apply for the difference I was entitled to in:

    1. HIV lump sum payments for myself,
    2. Lump sum payments for my late husband (a co-infected haemophiliac) and
    3. Regular payments for myself as a widow of a co-infected haemophiliac

65. I was told that they were working on an update for the backdated lump sum payments, and I would receive a letter outlining further information.

66. Although I received a letter regarding the lump sum payment owed to me, the letter did not include any information on regular payments as promised, or any information relating to the lump sum payments for my late husband. I sent a further email to EIBSS querying this.

67. EIBSS responded on 5 August 2021 stating that they did not have an update on the new bereaved partner payments, and that the Department of Health and Social Care decided that the lump sum payments will only be paid to beneficiaries who are currently receiving regular payments from the scheme. Therefore, the payments would not be paid to the estates of deceased beneficiaries.

68. I wrote back to them asking if this decision had been challenged, given that the Hepatitis C lump sum payments were paid to the estates of deceased beneficiaries. The decision to not pay the HIV lump sum is not only unequal and discriminatory to those who have lost loved ones with HIV, but it causes further grief and division within the haemophilia community. This affects widows like me who do not have children, as well as the parents of children who died.

69. The most recent response from EIBSS simply repeated the position that the lump sum was being paid to current scheme beneficiaries only to increase their payments to the same as someone who joined the scheme today, and that the payments were not being made to estates. As I set out previously, my complaint was that the payments were not additional sums but rather to rectify inequalities in the lump sums; this is why the payments were increased. The Hepatitis C lump sums had been paid to the estates of the deceased, and if the same was not done for the estates of those HIV, this would be discriminatory. In December 2021, with the support of The Haemophilia Society, I raised the matter at APPG on Haemophilia and Contaminated Blood.

Conclusion

70. We were infected by the NHS, through our husbands and partners, and we want support proper and adequate financial, medical and psychological support.

71. For that reason, I continue to advocate for the voice of HIV positive women, highlighting the specific research required for HIV and educating others on the impact of the contaminated blood issue, and the stigma and discrimination surrounding women in the community. I continue to do this because I feel I have no choice as other groups are not advocating for us.

72. I live in fear for the future. We campaign as we are concerned as HIV positive women who are outside of the system of support which, whilst imperfect, is in place through haemophilia centres for HIV positive haemophiliacs. I am not even linked to a Haemophilia Centre. Therefore, I am not part of a health centre and I have no social worker. The Haemophilia Society should be supporting us. I recently re-joined as member following improved relations with the new CEO who has actively engaged with me.

73. THT failed to support us, and they should not have control over the residual MFT funds.

74. I have concerns about our care and our condition going forwards, particularly in relation to the damage caused by early treatments. We want a care package and need to be cared for as the toll of long-term HIV infection grows.

75. My mother is 94 years old and has children including me who look after her. I have no children (as a result of contaminated blood products) who will care for me in the future.

78. One of the most important things that needs to come from this inquiry is that we need to have certainty over how we are to be cared for going forward.

Statement of Truth

I believe the facts stated in this witness statement are true and I understand that proceedings for contempt of court may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief in its truth.

Signed: **GRO-C**

Clair Walton

Dated: 27 April 2022