Witness Name: NICOLA LEAHEY Statement No.: WITN0223015 Exhibits: TBC Dated: 14 January 2025

## INFECTED BLOOD INQUIRY

## THIRD WRITTEN STATEMENT OF NICOLA LEAHEY

l provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14<sup>TH</sup> January 2025.

I, I NICOLA LEAHEY will say as follows:

I am a non represented core participant of the Infected Blood Inquiry.

- This is my third witness statement to the Infected Blood Inquiry. As set out in my first evidence in June 2019 (WITN0223001) I stated that on the 10th October 1975 | received a blood transfusion and was subsequently infected with Hepatitis C. I was diagnosed in 2009, treated with the horrendous Interferon and Ribaviron. So, fifty years later | am still bearing the scars and consequences of that day, both medically, mentally and financially. In January 2023 | gave my oral closing statement (INQY1000270) to the Inquiry prior to Sir Brian's conclusions and publication of the Final Report. I voiced my concerns, I made suggestions and listed my recommendations, I felt listened to and supported by the Inquiry team.
- The long-awaited Final Report was delivered on 20<sup>th</sup> May 2024, it was such a relief that finally the truth was out there, and our plight was recognised. The feelings of the whole community was emotional, jubilant, and euphoric. We felt

free of the burdens we had carried, we felt listened to, we felt justice! Little did we know that during the following days we would plummet yet again into despair and anxiety of the unknown. Not only did we have the uncertainty of our health and grief for those who had died during this long campaign but now we had the turmoil of the compensation details that were appearing. We had apologies from the initial government that insisted it was "working at pace" only to find nothing had been done. Then a change of government ensued, we had more promises and reassurances, but we were back in the dark tunnel of the unknown at the same time as facing our inability to control our own destiny and yet again expected to trust a system that continues to let us down.

3. During the 6 years of the Inquiry we had received support from the Inquiry team, the Red Cross, our fellow victims (both infected and affected). Victims of this disaster were firmly held centrally to the whole process. Suddenly there was a void in our lives, we were not being consulted, we were left with information about a compensation scheme that was not explained properly and no support details. The tables produced in those first few days immediately divided the various communities. It was seen to be a decision as to whose lives were more valuable than others. Surely infected is infected, dead is dead.

The Inquiry had found that this had been the biggest NHS disaster of all time, we had all suffered the same negligence, mistakes, cover ups and therefore we should all be treated the same.

4. Sir Brian recommended that the compensation scheme be delivered by an 'arms length body' (ALB) The 'Infected Blood Compensation Authority' (IBCA) was established. In my mind IBCA does not seem to be an ALB. I have been fortunate to attend meetings with both groups, my impression is that Sir Robert Francis and David Foley do not appear to have the control or authority I would have expected. When I have asked questions in the IBCA meetings they often reply that they need to ask the Cabinet Office. Could this be because they have been left trying to implement a compensation formula that was designed by a government committee, an 'expert panel' behind closed doors, a committee that we had no representation on and who's minutes have not been made available despite many Freedom of Information (FOI) requests? I therefore question IBCA's ability to be transparent. I would have also liked to have been privy to their Standard Operating Procedures (SOP).

- 5. My most recent concerns are about the alleged reports of the government trying to silence our community to avoid embarrassment over the delays in the release of compensation. I fear that the same institutional defensiveness and groupthink that caused the original scandal's cover-up are now hindering the scheme. This raises concerns about further delays, inequities in compensation, erosion of trust, and compromised transparency.
- 6. This latest revelation about the alleged actions adds credence to my recommendations for open communication with victims, independent oversight of the scheme, and a cultural change within government institutions to prioritise accountability and responsiveness. I urge for the government to address these systemic issues to ensure fair and prompt compensation for victims.
- 7. IBCA now seem to be changing the goal posts regarding 'Special Category Mechanism (SCM) payments. IBCA refer to the fact that they are working on the recommendations of the 'Expert Panel.' I challenge with my statement "whilst clinical staff are experts in their field, WE are the experts in our body, our feelings, our experiences." BUT we were not consulted in the formulation of a list of illnesses, conditions that we have had to endure over the years and continue to suffer until our deathbed. Why should we have to continue to jump through hoops, relive our stories and the subsequent struggle to gain recognition of our health issues, therefore imposing more trauma and anxiety upon ourselves?
- 8. The process of compiling the list of illnesses and conditions failed to include input from the victims. This fundamental flaw undermines the list's accuracy and comprehensiveness, as it overlooks crucial experiences and long-term

health consequences. This lack of consultation further exacerbates the trauma experienced by us.

- 9. A significant number of illnesses and side effects resulting from treatments remain unrecognised by government and the scientific community. This lack of recognition stems directly from the absence of clinical evidence. The absence of clinical evidence is not due to a lack of genuine health issues, but rather a direct result of insufficient government funding for necessary research and follow-up care. This systemic failure to invest in understanding the long-term impacts on the victims has added to a cycle of denial and neglect, reminiscent of the government's historical denial of the potential impact of Hepatitis C and the detrimental effects of early medical trials as contributing factors to this lack of research. Therefore, I suggest a thorough and sensitive consultation process with the victims must be initiated to accurately document the full range of illnesses and conditions they have experienced.
- 10. Following this consultation the government and relevant medical bodies should formally recognise the documented illnesses and side effects. This recognition should pave the way for improved access to healthcare, compensation, and other necessary support services, thus building trust for the victims and ensuring that we receive the care and recognition we so deserve.
- 11.1 am acutely aware and worried about the discrimination endured by the infected victims impacted by the inconsistency of the cut off dates within the English Infected Blood Support Scheme (EIBSS) and IBCA's directives, thus causing financial hardship and confusion. Sir Brian's recommendations (April 2023 and May 2024) called for the removal of cut-off dates from the compensation scheme and recommended Hepatitis C testing to those transfused before 1996. While the IBCA says the new scheme has no hard cut-off dates, the EIBSS continues to enforce the September 1991 date. This discrepancy leaves a vulnerable cohort in limbo causing extreme anxiety. The gap between the encouraging messages generated by Sir Brian's final report and the current inaction continues to cause significant distress.

- 12. IBCA are employing staff as claim managers. I am genuinely concerned that these people must be fully trained and conversant with the traumatic experiences that we have endured in the past and are now worsened by the current delays in delivering the compensation. The system that has been put in place for 'inviting' victims to claim their compensation has been flawed from the beginning. We are at the point where compensation is being offered whilst IBCA admits its actually still testing the system. Yet again we are being experimented on! Not only has it caused great divisions within the communities, but it has also exposed unfairness and disparity. The disparity in potential compensation amounts due to differing payment timelines (and the potential for investment interest accrual by early settlement recipients) is a significant inequity. I have raised this issue with both IBCA and the Cabinet Office, their reply being that they are acting as swiftly and as fairly as possible! They now answer this query by saying it would be too complex to calculate! So therefore, I surmise that through no fault of our own and yet again through organisational failures we the beneficiaries are the sufferers.
- 13. IBCA and the Cabinet Office now organise meetings with several of us and those representing campaign groups. At first, I was wary of the sincerity of these meetings, and I feared that they were merely performative and therefore wasting our precious time. But the most recent meetings I have attended have given me more hope that they have listened, but we need concrete action to restore our trust; but we are still left with a compensation formula designed behind closed doors, now legislated for, that IBCA cannot change.
- 14. In June 2024 I was invited to be involved in the NHS England (NHSE) development of a national 'Infected Blood Psychological Support' (IBPS). It was welcomed that they were wanting to hear about our experiences and how they can establish a network of professionals to support us. This service is due to be completely rolled out in Spring 2025, with a couple of areas trialling it already. This service should have been set up years ago. In December 2024 I

attended a training day for the first batch of recruited professionals. I explained to them that they could be dealing with vulnerable infected and affected victims that have lost faith and trust and even more so now in the current climate of compensation uncertainties. The fact that compensation may help people financially does not solve the everyday anxiety, vulnerability, and despair that many of our community feel and experience.

- 15. IBCA should have been in dialogue with IBPS much earlier to use their expertise and to ensure a holistic approach to supporting the needs of the infected blood community.
- 16. At 73 years old, I must emphasise the profound physical and, more importantly, psychological toll this protracted process has taken on me and countless others. The repeated disappointments and systemic failures have caused immeasurable pain, anxiety, and disillusionment. We, as a community, deserve to live our remaining years free from this ongoing trauma and with a sense of peace and closure. We urge immediate and decisive action to ensure this becomes a reality; to ensure that this Inquiry becomes an effective instrument to hold the government to account and an example for future inquiries; that all recommendations are actioned and not side stepped nor deliberately swept under the carpet!
- 17. My conclusion is that there are critical issues surrounding the IBCA's operation caused in part by governmental restrictions and a poorly designed compensation formula plus the critical lack of funding (caused by the previous government failing to ring-fence any budget for implementing the recommendations of the inquiry); all of which impact on the infected blood community.
- 18. Addressing these concerns through increased transparency, genuine victim consultation, and a more equitable and efficient compensation process is essential to restoring trust and providing meaningful redress for the harm caused.

19.1 am hopeful that my statement serves as a basis for further investigation and action.

## Statement of Truth

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

Signed	GRO-C	
Dated	19th February	2025

Table of exhibits:

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Date	Notes/ Description	Exhibit number
18/06/2019	First written statement of Nicola Leahey	WITN0223001
26/01/2023	Closing statement of Nicola Leahey, entitled "Blood is the River of Life"	SUBS0000047