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***Saunders Law submissions:***

***On prioritisation of claims and the IBCA***

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*Introduction*

1. It bears saying that the fundamental issue with IBCA scheme is that it was set up as a departure from the Infected Blood Inquiry (“IBI”) process. By its failure to consult with those infected and affected in the very constitution of the scheme, the government departed from the hallowed foundation of the IBI – that of putting those infected and affected at front and centre in the quest for full moral compensation. The government opted for secrecy over transparency. Even by its choice of a defendant law firm for advice in setting up the scheme, they signalled the adoption of a restrictive course of control in doling out compensation, within the paradigm of personal injury litigation. To date, it has seemed like history repeating itself, again.

*Principle*

2. The basis in principle for objection to the IBCA’s process of prioritisation of claims flows from the fact that the scheme was set up without due consultation with the parties it was meant to serve. It is axiomatic that those who have waited four decades for

compensation would have some thoughts about how the process that so deeply affects them should be implemented. Timeliness has always been key. Without knowledge of the lived experiences of those infected and affected – and an appreciation of its complexity - there can be no technocratic fix from any government scheme, that ends up delivering justice. The inconsistencies, confusion and gaps in the scheme are all predictable, when you consider that it was stitched together on the advice of an Expert Body that was forbidden, by its own terms of reference, to consult with those who are infected and affected.

### *Re-inventing the wheel*

3. One of the main sources of agitation during the IBI was the need for a system of compensation that didn't require victims being put to proof, in the manner of a bog-standard personal injury claim. Such a course runs the risk of re-triggering people who have already endured years of trauma.
4. Victims of this scandal have amassed significant bodies of evidence through engagement with EIBSS and other financial schemes. It was submitted at the IBI that this should establish a presumption in favour of eligibility. Previous engagement with EIBSS should preclude need for the provision of information such as a date of diagnosis. One member of our cohort has been asked to establish the date of diagnosis for both his hepatitis C and HIV. It may be that the haemophilia centres or EIBSS can play a part in

standardising the process of proving infection based on existing records.

5. Our clients are of the view that the date of diagnosis should not play an outsized role in determining the value of a claim. If it is imperative that a date of diagnosis is known, then the date of infusion should be used across the board. The experience of the IBI has established that in many situations, testing likely occurred only after one had already been infected and contracted the condition.
6. Our clients are of the view that there is need for guidance on the use of proxies, in proof of eligibility. Use of interferon to clear hepatitis C, for example, could conceivably be a way of establishing infection by hepatitis C. The lived experience of one member of our cohort was that he took interferon but did so for the briefest of periods, as – as with so many others – it was monstrously unbearable. Guidance will need to be alive to the fact that this happened a lot: an attempt to use interferon to clear hepatitis C, that was soon quickly abandoned. Our clients are of the view that interferon usage should still be used as a proxy marker even where it was short-lived. Similarly, guidance will need to also be nuanced in discussing proxy markers for liver disease, describing living with the consequences of AIDS, permanent

effect from an opportunistic infection, permanent side effects from medication and so on.

### *Penalisation for complexity*

7. Our clients have lived for many years with comorbid infections and are at higher risk for developing multiple illnesses. They are at high risk of opportunistic infections. Two members of our client cohort have been particularly susceptible to heart related issues – and one succumbed to a resulting illness. There are usually no warnings or symptoms. The 12 months banding for illnesses does not make space for such illnesses which may be immediate, symptomless, and where progression is rapid.
8. Our clients have been left with the view that the IBCA penalises those with complex conditions. There are resulting illnesses that they experience which are not listed in the core banding. The distinction between the core and supplemental route seems arbitrary and proving the progression of a condition under the supplemental route is onerous.
9. One member has raised the fact that he has secondarily developed cryoglobulinemia, a rare condition characterised by the presence of cryoglobulins in the blood, which resulted in him needing a kidney transplant. Going through the paces of processing his IBCA claim, he has constantly been asked to provide evidence of how this is linked to infected blood. Biopsy is the way to fully prove the

connection between the infected blood and the condition, but this is not possible for him as a haemophiliac. He has obtained confirmation from his renal consultant about the link between his condition and infected blood. This member was awarded £60,000 as an ex-gratia payment from EIBSS, based on the evidence that he had; but this does not appear to be sufficient for his IBCA claims manager.

10. It is noticeable that IBCA seem more adept at dealing with liver issues (including cirrhosis), not those affecting the kidney. The banding for example, solely focuses on the deterioration of the liver and ignores the impact of hepatitis C on the renal system. The IBI documented countless stories of hepatitis C leading to renal failure and ultimately, the need for a kidney transplant.

### *Ignoring mental health*

11. The IBI uncovered the resulting mental health catastrophe that accompanied the infected blood scandal. It catalogued the decades long trauma of mental health suffering that came out of these events; and the absence of support, in the wake of government refusal to accept responsibility. As such, there are only few stories of appropriate engagement with mental health support among victims. The government was specifically urged not to approach compensation, especially for mental health suffering, using the personal injury paradigm, as it was anticipated that the

absence of engagement with psychiatrists would be a bar to advancing claims for mental health suffering.

12. The IBCA does not make sufficient provisions for factoring in mental health through both its core and supplementary routes. This is not satisfactory, in the wake of all the evidence heard in the IBI on this subject.

### *Submissions*

13. Our clients acknowledge the rationale behind the IBI's proposal for the prioritisation of claims, but respectfully suggest that the following groups should be considered when deciding the prioritisation of claims:

- i) People with a terminal diagnosis as is the current prioritisation;
- ii) Those over 80 years old;
- iii) Cirrhosis proxy – those who received the stage 2 payment under the Skipton Fund, when it existed;
- iv) Kidney complications and kidney transplant proxy;
- v) Family members of the person (where they are happy for this) doing all claims together at the same time.

14. The IBCA consider that the IBCA should be invited to immediately:

- i) Open applications for people alive, infected and not registered with any scheme, for example those with mono-infection of chronic HBV.
- ii) Open registrations for affected. This will require details of the person they are related to and details of their oldest beneficiary and any diagnosis of 12 months to live among beneficiaries. They should be paid at the same time as the person to speed up the process.
- iii) Continue to process applications on behalf of the estates of the people who died after being invited but before accepting their offer, at the same level of award as if the person were still alive.
- iv) Set up an appeal body within IBCA that can review appeals if the medical assessor refuses or is uncertain about the application.

### *Conclusion*

15. The Inquiry is invited to adopt these concerns in a further report.

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**May 23, 2025.**