

23rd May 2025

Dear Sir Brian,

We are writing in response to your request for further submissions, following the Inquiry hearings on 7th and 8th May.

The intention of this letter is to supplement the evidence previously submitted to the Inquiry, and the evidence given by Samantha May on behalf of The Hepatitis C Trust. We will therefore not reiterate the information contained in that evidence.

We would also note that this letter is made in addition to the recommendations contained within the submission of the Leigh Day Core Participants, to which we have also contributed and which document our proposed recommendations.

We want to highlight specific concerns and suggestions stemming from the recent hearings, and the evidence presented in advance of them.

Firstly, we wanted to raise the issue of delivery of compensation.

We welcomed the Minister's commitment to delivering compensation rapidly but we're very concerned by the Government's apparent willingness to forego justice in favour of speed. Rapidly paid compensation which does not reflect the true damage done to people is not meaningful compensation.

We believe there are opportunities both to speed up delivery of compensation and – simultaneously – review the underpinning compensation framework to ensure that the sums offered properly reflect the harm done to individuals. There are many opportunities to achieve both of these aims, many of which are covered within the Leigh Day submission.

We would specifically ask that the forthcoming report recommends the adequacy of compensation for hepatitis B and C are reviewed, in particular the complexity of the tariffs and what this means for the quantity of evidence required from people applying for compensation, the change in Financial Loss associated with the introductions of new treatment for hepatitis B and C, and the significant difference between the Special Category Mechanism and the Severe Health Award qualification

PATRONS

Ms Sadie Frost
Boy George
Mr Robbie Williams
Miss Emilia Fox
Mr Alan McGee
Ms Justine Roddick

The Lord Mancroft
Mr Andrew Loog Oldham

TRUSTEES

Sir Adrian Baillie
Hon David Macmillan
Mr Peter Holt
Mr Edward Mead
Mr Charles Walsh
Mr John Jolly

criteria. People already accepted as qualifying for the Special Category Mechanism should be accepted as qualifying for the Severe Health Award. These changes can both expedite claims and provide a more just reflection of the damage done to people's lives.

We would also suggest that the rationale for the single tariff for people who died of acute hepatitis B within 12 months of infection is also examined. This is extremely low in comparison to other awards.

The importance of some degree of discretion being made available to the IBCA cannot be overstated. Since giving evidence, we have continued to hear from people greatly distressed by their exclusion from the Severe Health Award, for example one person who lost their eyesight as a consequence of interferon treatment; under the current system this cannot be compensated. It is impossible to codify every possible consequence of hepatitis C and interferon treatment in legislation; this can only be addressed through a degree of discretion, with effective clinical input, in making awards.

We have also had concerns raised about the training and qualifications of the Clinical Assessor within the IBCA. We are informed that all clinical decisions are currently made by a single individual, and their background training, knowledge and skills in relation to all conditions relevant to infected blood, and of the infected blood community and scandal, is not clear.

We also wanted to provide an update, and some reflections, regarding the Government's response to Recommendation 10 (c). As highlighted in our previous evidence, the demand on our services over the past year has been exceptionally high. We cannot sustain the work we are currently doing, which is unfunded.

As detailed by Kate Burt, CEO of the Haemophilia Society, at the Inquiry hearing on Wednesday 7th May, on the Friday prior to the hearings The Hepatitis C Trust, Haemophilia and Thalassaemia Society received letters from Rt Hon Ashley Dalton MP, Minister for Public Health, stating that funding for a one year grant of £500,000 had been identified, to be divided between the three charities. While we very much appreciate this potential funding, we found both the timing of this letter and the sum concerning as it indicates very little had been done to understand the work we are doing or to quantify how this should be funded, despite our having met with DHSC officials and submitted details of our advocacy work and its associated costs.

We made it clear to the DHSC that, however divided among the three organisations, the sum does not adequately reflect the scale of needs at the current time, and that funding for only one year when the Inquiry is ongoing and IBCA are currently estimating they will need 5-6 years to deliver compensation was wholly inadequate. and none of the organisations accepted the sum as proposed. Following this, the Minister for the Cabinet Office announced that DHSC was "now meeting the charities to begin the grant process to finalise the awards," which we felt was premature. It seems that this funding has been put forward without any detailed

planning; a sum of funds has been proposed with the seeming assumption that the charities should divide this among themselves, and without adequate understanding of the importance of our work to advocate for the community. We have asked the DHSC to review this and these discussions remain ongoing. We remain concerned that the intent is to provide a small amount of short-term funding, sufficient only to announce that Recommendation 10 has been met.

Finally, we would underscore your important point about listening to – and hearing – the community.

As has been demonstrated time and time again, people impacted by infected blood are eager to engage and help shape decisions around compensation and the wider inquiry response. They also have huge expertise and insights which could well have serviced to highlight and address the flaws in the current compensation system and wider response to the Inquiry recommendations.

We would ask that the Inquiry is very clear about the critical importance of meaningfully involving community members in any and all changes that occur henceforth.

We extend our thanks as ever for the work you continue to do in ensuring the terrible events of the Infected Blood scandal are fully understood and that your recommendations are acted upon. As was clear from the standing ovation on the 7th May, the Inquiry's work is deeply appreciated to all of the people involved.

Yours sincerely,

GRO-C

Rachel Halford, CEO

GRO-C

Samantha May, Helpline, Information & Support Service Manager