Ms Ellie Nicholson
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Cabinet Office
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Dear Ellie

I look forward to discussing the Haemophilia Society's (THS) submission on the government's proposed changes to the Infected Blood Compensation Scheme when you and the Paymaster General, Nick Thomas-Symonds MP, visit our office later this week.

I am conscious that you will have received a significant number of letters in response to this consultation, many of which express strong views on behalf of broad coalitions or campaign groups. While the strength of feeling behind those representations is understandable as opposed to signing any joint correspondence, the Haemophilia Society has taken the time to consult directly with our members, analyse the consultation proposals in detail, and reflect on the practical and evidential lessons of past schemes that have failed this community. The positions set out below therefore represent the considered views of our survey responses and past experience. The below was reflected in detail in our submission and will be publicly available on our website.

Special Category Mechanism (SCM) and equivalents

The Haemophilia Society (THS) supports automatic qualification for those already assessed as eligible for SCM or equivalent schemes.

However, linking payment start dates to the point of SCM assessment is fundamentally unfair and cannot stand. SCM did not exist until 2019, long after many individuals had already experienced serious deterioration. Compensation for additional suffering must begin from the point at which symptoms first manifested, based on clinical evidence, not from the date the state eventually chose to recognise them.

Estates

We think the same rules should apply to estates, where people were accepted onto SCM and the payments backdated to the time when the health of the person had clinically deteriorated.

Extension of SCM eligibility

SCM Severe Health Condition awards must be extended to living infected people not registered with an IBSS, including those with chronic hepatitis B who were historically excluded from support.

Any new assessment process must not repeat the failures of earlier SCM schemes, which were characterised by opaque decision-making, inconsistent outcomes, inaccessible evidence requirements and the absence of a trusted route to challenge decisions.

Devolved schemes should be treated as the benchmark. People in England should be assessed to equivalent standards to achieve genuine UK-wide parity.

Financial loss and effective hepatitis C treatment

THS cannot accept reductions to financial loss awards following the introduction of effective hepatitis C treatment in 2016/17.

Most affected people were treated long before this date, often with interferon, and never received the treatment on which the reduction is based. Viral clearance does not undo physical, cognitive or psychological harm, nor does it restore lost earning capacity.

Financial loss compensation for those accepted onto SCM or equivalent awards should therefore be set at 80% of the national average wage, without post-2016 reductions.

Domestic support and ad hoc care

Six hours per week of domestic support must be treated as a baseline, not a ceiling. Where evidence demonstrates greater need, access to higher care bands must be available. A rigid cap does not reflect lived reality.

Severe psychological harm

Individuals previously awarded SCM on mental health grounds must be fully recognised within the Severe Health Condition framework, with aligned start dates and payment levels.

The exclusion of individuals rejected from SCM despite clear evidence of additional psychological harm is unacceptable. IBCA must apply a flexible and compassionate approach to evidence. Reliance solely on consultant psychiatrist reports is inappropriate. Primary care records, haemophilia centre notes, counselling history, long-term antidepressant use and evidence of suicidal ideation must be accepted.

Harm caused by interferon treatment

Interferon treatment caused profound and enduring harm. Assertions that symptoms typically resolve after treatment are inconsistent with lived experience and the evidence presented to the Inquiry.

All individuals who underwent interferon treatment should be placed within Level 3 compensation, with payments starting from the date of first treatment. Creating additional sub-bands would add unnecessary complexity and delay.
In addition, a substantial lump-sum award is required for all individuals, living and estates, who endured interferon or dual therapy, to reflect the severity of harm and the impact on families.

Past financial loss and past care awards
The community must not be forced to choose between inequitable options. A single fair model is required, one that treats living infected people and estates equitably and does not penalise individuals for dying early.

Exceptional Loss
Exceptional Loss must be assessed realistically and not confined to historic payslips alone. Evidence should include qualifications, industry pay scales, HMRC and Companies House records, and pension impact. IBCA must be resourced with appropriate specialist expertise to assess these cases fairly.

Supplementary awards for affected people
A tariff-based approach is essential to avoid intrusive and protracted individual assessments. Higher awards should be made automatically to clearly defined groups, including children of infected parents, affected partners and dependents, disabled dependents, and those whose careers were damaged by caring responsibilities. Historic lack of mental health support must not bar recognition.

Unethical research
Eligibility for an Unethical Research Award must not be restricted by an arbitrary cut-off date. Evidence demonstrates that unsafe testing continued beyond 1984.
The proposed award value is wholly inadequate. Being subjected to unethical research without consent represents a fundamental betrayal and requires far stronger recognition.

Loss of Potential – children infected
THS demands the creation of a specific Loss of Potential award for those infected as children, including estates.
Children infected with contaminated blood were harmed at the very point when education, development and opportunity should have been protected. These harms are not captured by existing loss of earnings or exceptional loss frameworks.
The current scheme fails children by design. Loss of earnings is not recognised until the age of 16, as if harm only begins at that point. This is grossly unfair and ignores the reality that childhood infection fundamentally altered life trajectories years earlier, before any earnings history could exist.
For those who died young, this potential was never realised, yet its loss is undeniable. Children infected as a result of state failure should not be required to evidence a career they were never given the chance to pursue.

Other

Acute hepatitis B must be included as a qualifying condition, and hepatitis D co-infection recognised at the same level as chronic hepatitis C.
Current inequities affecting estates and bereaved families must be addressed, alongside appropriate resourcing for haemophilia centres and practical support for estate executors.

I look forward to discussing these matters further with the Paymaster General, Nick Thomas-Symonds MP and your officials later this week. I would also like to thank you again, Ellie, for attending our recent Big Get-Together conference last November which you will know was the most highly attended event we have held in many years.

Yours sincerely

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