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INFECTED BLOOD INQUIRY

EXHIBIT WITN7765002

Mono-HCV Infected Haemophiliacs

Sir Brian Langstaff

Infected Blood Inquiry
5th Floor
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28th March 2025

Proposal for recognition and fair compensation of mono-HCV infected haemophiliacs

We are a small group of haemophiliacs who were infected with Hepatitis C (HCV) through contaminated blood products.

What unites us is that we are the haemophiliacs who were **not** infected with HIV.

We believe we have been overlooked in the current compensation proposals, so we are writing today in the hope of correcting what we believe is a serious miscarriage of justice.

At present, our minority group of mono-HCV infected haemophiliacs have been grouped together with the vast number of transfusion recipients. We believe this drastically misrepresents the severity and scale of our losses.

Key points of difference

1. Route and nature of infection

Mono-HCV infected haemophiliacs were treated repeatedly, not just once but time and time again with contaminated commercial Factor VIII at a time when it was widely known these products were infected with non-A non-B hepatitis and HIV. This was both negligent and reckless. The Department of Health chose not to heat treat Factor because it was deemed too expensive, and they chose not to use safer options such as Cryoprecipitate and DDAVP despite many managing perfectly well on these products.

Most of us were infected as infants so have never experienced life without hepatitis.

There appears to be a critical misunderstanding that haemophiliacs infected with contaminated blood were co-infected with HIV and HCV. This assumption is wrong and has led to the serious neglect of the mono-HCV haemophilia community.

The tariff system as it stands groups us with whole blood claimants despite our journeys being vastly different. Haemophiliacs were deemed expendable, a burden to the NHS. The psychological impact of coming to terms with being considered worthless has been, to say the least, challenging.

The government chose not to protect us in the 70's and 80's and are choosing to treat mono-HCV haemophiliacs with the same contempt today.

2. *Subjects of research*

The haemophilia community were subjects of research, we were guinea pigs, even as children (and far more widely so than is being acknowledged). PUPs were recruited onto formal trials such as the Kernoff Study without consent and blood tests for HIV and hepatitis were being taken without consent at all hospital reviews.

3. *Social isolation and stigma*

Haemophiliacs need to wear Medic Alert bracelets. As children, many of us carried them in our pockets to avoid awkward questions. Just knowing you were 'different' was bad enough, so we would do anything we could to avoid the whole school finding out. Despite this, first day of term assemblies always ended with the announcement of our presence and the importance of avoiding hurting us in the playground. It was humiliating. This got worse in the 80's with the tombstone ads, and incredibly to this day children are still being called 'AIDS kids' in the playground. None of us escaped the bullying, HIV positive or not.

Being infected, on top of being haemophiliac has led to our lives being defined by shame, fear and secrecy. The impact has been profound both socially and psychologically. This simply cannot be dismissed or devalued in the way the regulations are allowing it to be, we've waited far too long for recognition.

4. *Damage to our careers*

As haemophiliacs, most of us kept our conditions secret when seeking employment. Even to this day, if you mention haemophilia, you see that look in their eyes and find yourself quickly explaining that you're not contagious.

Of course, employers are cautious, so we soon learned it was best not to mention our condition at all.

Bi-annual haemophilia centre reviews, orthopaedic clinics, even surgeries were blamed on dental visits or arthritis. But the treatment of hepatitis was harder to disguise. Dealing with one or the other was manageable for some, but together, we didn't stand a chance.

This resulted in lost opportunities, promotions that didn't happen, jumping ship to higher paid roles elsewhere was simply too risky. Treatment of hepatitis on top of haemophilic issues became too much for many of us and careers came to an end.

5. *The Expert Group*

When the Expert Group was established, the haemophilia community were horrified to see there was no representation of our community on the panel.

We cannot understand why it was deemed unnecessary to include a representative of the group that initiated the Infected Blood Inquiry.

How can it be that the shaping of a scheme, 50 years overdue, can take place without the presence of someone that specifically understands what we haemophiliacs have been through?

Conclusion

HIV-infected haemophiliacs are set to receive up to £29,000 per year, with comprehensive recognition of the systemic failures and lifelong impact.

Mono-HCV infected haemophiliacs, by contrast, are offered as little as £6,000.

This disparity is indefensible. While we recognise the unique trauma of HIV, it must be acknowledged that mono-HCV haemophiliacs suffered many of the same violations: lack of consent, multiple infections, concealment of diagnosis, lifelong ill health, stigma, loss of career, and in many cases, psychological collapse.

We are not transfusion claimants. We are victims of systemic failure and have lived a lifetime with the burden of government negligence and denial, on top of our debilitating disability.

We are not asking for a complete rewrite of tariffs, and we certainly do not wish to cause delay. We simply request that mono-HCV haemophiliacs (we estimate there to be about 50 of us) are recognised.

Our infection profile, treatment history, and lifelong harm sets us apart from the wider Hepatitis C group. Our education and careers were damaged beyond repair. We seek justice for those who have spent a lifetime living with illness, secrecy and disadvantage.

We make one simple ask that the second set of regulations are amended for some discretion through IBCA to look at the financial loss for mono-HCV haemophiliacs whose education and or career was disrupted, without the requirement to produce five years worth of payslips which for many is untenable. The current system penalises those who were most severely impacted.

There needs to be an element of individualised assessment. All the charities suggested the scheme should have a tariff-based structure with an element of personalisation. We have an exceptionally rigid scheme which penalises and discriminates the most seriously impacted in the haemophilia community.

As you know ITV will soon be screening a documentary on Treloar's and a drama series on the wider community, written by Peter Moffat is scheduled for later in the year.

We believe accommodating our request could:

1. Show your commitment to haemophiliacs and reduce the inevitable backlash that will follow these screenings
2. Minimise the risk of further reputation loss to government by avoiding inevitable class litigation being initiated by our cohort.
3. Help demonstrate the governments adherence to the recommendations outlined in the Inquiry Report.
4. Avoid media attention regarding the inadequacies we believe exist at present.

**On behalf of
Mono-HCV Infected Haemophiliacs**

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