

GRO-C

20th April 2025

Sir Brian Langstaff
Chair, Infected Blood Inquiry
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Dear Sir Brian,

I have thought long and hard about whether to contact you regarding the ongoing situation with compensation. I am sure a lot of this will duplicate much of what others have told you, but should you wish to use any of the following, you are very welcome to at any time and in any way that you see fit.

On 20th May last year, the feeling amongst the community was one of gratitude and euphoria. We felt both valued by the Inquiry team and vindicated, in that everything we had been saying for decades had proven to be correct. However, the government's rushed announcement regarding compensation the following morning left our world crashing down. We soon became aware that the compensation tariffs had been decided before government had even read your Final Report, despite months of delays during which we were constantly told that they were waiting for the final outcome before they made any decision. This was clearly not true.

Moreover, we then found out that the Expert Group appointed by the government were to have the benefit of anonymity – something that had long been denied to many campaigners. Since the 1980s, many of us have shared intimate and traumatic details about our lives to the press and government - in fact to anyone who would listen, yet this body was to be protected by government, including those we know to have had previously involvement with pharmaceutical companies such as Bayer – something which we would have vehemently challenged had we been given the opportunity.

It is complete nonsense that the community were involved in the formation of the scheme. We were not. It was thrust upon us with no meaningful consultation and consequently was, and is, full of anomalies, flaws, and a lack of clarity. I was appalled to learn recently that Government had employed solicitors to advise them on the new scheme well before February 2024 (which was some three months prior to publication of your final report) – yet our access to legal advice is still limited – to the point where we are not being offered funded legal advice until *after* we have signed the critically important “declaration” form.

The effect on our community has been devastating. In 40 years of campaigning, I have never witnessed such distress, confusion and despair. This includes long-term campaigners, some of whom have had to step back in order to protect their mental and physical health. I myself previously felt that I could contribute usefully to the campaign, but over the last few months I have become more and more confused and disillusioned, taking a less active part.

It seems to me that the government is doing their best to save money at the expense of those they have so grievously harmed. Widows simply do not know whether they will live long enough to see an individual payment. Kitty Stewart, who died recently, having lost her husband and one of her sons, did not live long enough to receive a payment and her potential claim died with her. The recent death of a long-term campaigner, a friend to many of us, completely devastated those of us who knew him. He did not live long enough to benefit from the compensation he had fought so hard for, and yet again we have another widow and more bereaved children left with no real answers. The longer these payments take, the more government benefits. We have asked for interest on our claims to be paid in proportion to the amount of time we have had to wait, yet this has been denied to us – how can that be right or fair? Surely it is not beyond the grasp of government to realise that people could be losing very significant sums of money because of delays, and because potential claimants are unable to take control of their rightful award and invest it properly.

Many widows and parents are now elderly and in poor health, and yet, the latest move by IBCA to identify those near end of life, whilst in one way is welcome, completely excludes the affected. We have been left in limbo, unable to make plans, unable to prepare for our futures however long or short they may be. Furthermore, the criteria for deciding that someone is at end of life appears to be overly complex and necessitates high-level medical opinion/certification. It completely ignores the fact that end of life cannot always be predicted in such a clinical way; for example, many widows are now in their 80s and 90s, in other words, close to the end of their natural life. Our friend who died recently, had not been given an end-of-life diagnosis that would have been in accordance to the new IBCA criteria, yet he died unexpectedly in his sleep.

It was recently pointed out by the wife of a desperately sick man that end of life is very hard to predict, and thus such a diagnosis is unlikely. It is my opinion that the criteria set by IBCA needs to take a far more generous, holistic and common-sense approach to determine what should be deemed end of life. Not everything falls into neat categories.

Let me be clear, I do not entirely blame IBCA for this. The government should have set up the compensation scheme at the latest immediately following your second interim report of April 2023, had they done so, and had they involved us in the formation of the scheme, many problems currently being experienced would have been avoided.

Although the following would not be popular with everybody, I remain adamant that those already registered with the existing schemes, and who have already received payments, should be dealt with first. All of us in this category have an established history, including medical records etc, and yet we heard this week that case advisors are helping one person, a whole blood recipient, who has not even managed to get hold of any medical records. This cannot be right! The haemophilia community, in particular, is a finite group, whose history

was well-established long ago and whose cases should be the easiest to deal with first. It is also a group that is more likely to suffer co-infections and co-morbidities - yet again this is well-known and understood, and this is not the case with whole blood infectees whose history is not so well documented and where the root cause of infection is not always easy to identify.

I find it difficult to understand why IBCA are apparently taking a random approach when calling people to make their claim. Surely common sense would dictate that they should start with those who already have an established history under the present schemes, whilst paying particular care to identify the very elderly and the very sick? This way they will be able to speed up the entire process, allowing them to devote time later on to those who need more help in locating evidence?

I, like so many others, am appalled at the low and discriminatory payments for those subject to unethical research. It has been clear to us for many years that the haemophilia community, including spouses/sexual partners were ALL subject to research which in my opinion is in breach of the Nuremberg Code, and which gives a stark reminder of experimentation by the Nazis in World War II. I can provide written proof that at least one nurse at the Oxford Haemophilia Centre was tasked with doing research on infectivity rates between haemophiliacs and their sexual partners, yet we are not recognised at all. If the current rates of pay for unethical research are allowed to remain, this will effectively give the green light to the medical and scientific profession, along with the British Government, to experiment on future patients without their consent. The consequences of past actions must be greater in order to avoid a repeat in the future.

The last point I wish to make is about the projected timescale for paying out claims. We are in complete despair over this, as many of us will not live long enough to see our final award paid out, let alone, being well enough to use the money as we would have wished.

Finally, Sir Brian, I want to say thank you for recalling the Inquiry and for your foresight in keeping it open in the first place. It is reassuring to know that you will once again be listening to evidence and will hopefully have the opportunity to follow this up and put pressure on wherever it is needed. I want to reinforce to you how very much we all value your tenacity and determination to see this through.

Yours sincerely,

GRO-C

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