



10 December, 2024

Dear Sir Brian

**Ref: Psychological impact on the Infected Blood Community**

I hope this finds you well and that you managed to have a good and very well-deserved break over the summer, post the Final Report.

Since then, so many people in this community have been challenged, being re-triggered, especially through seeing in black and white in the Final Report, information which related to them or their loved ones with emotions they might have thought long buried rising to the surface as if they were back in that traumatic time, once more.

To add to this, currently, this community is also experiencing a great deal of anguish caused by the delays and lack of clear information being provided about compensation. Due to this, I wanted to write to you, in addition to the campaign groups and other organisations such as the Haemophilia Society and the Hepatitis C Trust, to share with you a snapshot of the psychological and psychosocial impact the current situation has been having on this community and also to highlight issues we as HBDCA, and our clients, are facing due to decisions made with regard to EIBSS.

HBDCA is having conversations, on a daily basis, with many individuals; distressed, dismayed, confused, angry and upset. Nearly eight months after the Final Report was published many of them are none the wiser about whether they will actually be awarded any compensation, or when that might be, and that they might not live long enough to receive any, and are also worried, if they currently receive monthly payments, that they might actually be worse off. People are living in limbo, unable to move forward in a positive direction, or to make plans for the future, whilst so much is still so uncertain for them. This has had a huge and detrimental affect on their psychological wellbeing.

Many people are also still not at all clear about their legal and financial rights and are not confident, when they do finally receive any compensation, that sound financial advice will be made available to them. This is especially important for people who may need to plan for future healthcare needs, to ensure they have enough funds to sustain any costs which might arise for long-term care etc.

One has to also bear in mind that there are many in this community who were unable to work, due to their ill-health and stunted education, who have never been able to afford to buy their own home. I have had real concern voiced to me by people in that situation that they are worried they will do the wrong thing with the compensation they receive and will end up spending it on trivial things rather than purchasing a house, for instance. They are concerned that through lack of advice they may make some unwise decisions and will be left with very little, with the financial security and safety net they all so deserve falling away, especially of owning their own home, after nearly a life-time of living hand to mouth.

Two vulnerable groups I am concerned about are the parents of children and also the children of parents who died. Children and elderly parents have already waited far too long for recognition of their experiences. For any parent, the loss of a child is the very worst thing that can happen, yet they seem to have been left at the bottom of the pile, along with the children, and many elderly parents may pass away without ever receiving a full acknowledgement of what they went through, or the granting of compensation which should have been organised in as timely a manner as possible. And in as straightforward a process as possible, bearing in mind the technical aspects of this process are a minefield for those younger in the community, let alone for a widow, for example, living on her own, in frail health.

With regard to EIBSS, HBDCA clients are soon to have challenges with funding for psychological support post 31 March, 2025. Having requested a meeting several weeks' ago on this issue, in order to clarify the situation, with NHS England and with a representative from EIBSS they both confirmed that after 31 March, our clients will not have the ability to apply for further funding and will be assigned instead to the new IBPSS. There is a small breathing space in that EIBSS confirmed that any of our clients applying before 31 March will be eligible for a further £900.00 (i.e. one year's support beyond 31 March), but I strongly believe that any of our clients who wish to remain with HBDCA should be allowed to do so, and funding made available for this, beyond that one-year period. NHS England and EIBSS, at my request during that meeting, were going to organise a meeting with HBDCA and the Department of Health to discuss this situation, but this meeting did not

materialise. The principle that is exercising me is that members of this community should not have a psychological service route imposed upon them when they might already access high-quality, sound psychological support from a trusted provider which will be taken away from them without this funding. There should be choice for anyone who is currently receiving psychological support from whatever source that might be and who would wish to remain with that provider.

For a community where so much choice was taken away from its members, and where decisions were made without their consent or consultation, I believe this is ethically wrong and irresponsible. Especially, where they have built up a level of trust, for instance, with their HBDCA psychotherapist. Instead, they will be expected to now meet with someone new and start all over again.

There should be funding made available so that HBDCA clients (which is a small number – approximately 30), or the clients of other organisations or psychologists/psychotherapists, should have the right to remain with that provider, should they so choose, for five years if required, not just one further year, so that this continuing provision is equitable in terms of the length of time of the planned 5-year IBPSS service. I rarely blow HBDCA's own trumpet, but I can guarantee that 100% of our EIBSS clients will wish to remain with the HBDCA team with whom they have developed a great rapport and trust.

HBDCA has been involved as an NHS England stakeholder member since the beginning of those meetings and has demonstrated our willingness to co-operate, to collaborate and to share insight with our NHS colleagues in order to try to make the IBPSS the best it needs to be for the IB community. However, HBDCA is, amongst other things, still advocating for the importance of regular, regional, in-person peer support meetings for the different cohorts, but are not at all sure these will come to fruition.

Two meetings I was due to have to discuss this matter with NHS England and the IBPSS psychologists did not, in the end, happen. The meeting might still potentially happen but I am still waiting to have confirmation back from NHS England. HBDCA has facilitated several Infected Blood Days at the Haemophilia Centres we work with and they have been very well-received and much-needed. We will be running a follow-up event for each of those Centres in the next month or so to further provide support and also to further measure the psychosocial impact on this community, eight months down the line.

Please take my comments into consideration, Sir Brian when considering how severely, psychologically impacted this community is. May 20 was a red-letter day but I had been predicting for a long time in advance of that day, hence HBDCA's three-day presence at the Final Report, that psychological support would be needed from 21 May, and that the publishing of the Final Report and the government's response to it, would not be the end, but the commencement of a new, potentially difficult phase which would need to be managed. During these past eight months psychological and psychosocial support is still not readily available to most people, at such a vulnerable time.

My team, our Trustees, especially Joseph Peaty, and our Ambassador, Ros Cooper, both from the Infected Blood community themselves, and myself, continue to strive tirelessly for this community. None of us could have imagined how challenging these recent months would have been. I am very proud of HBDCA, especially our expert, kind and empathetic psychotherapists, and the fact that, despite being a tiny charity, we can hold our head up high with all we are trying to do, and have done.

HBDCA's current, valid concerns and those we are being made aware of on a daily basis by the clients in this community we serve, are a long way from yet being addressed and resolved.

HBDCA so appreciates what an incredible job you and your team have done and that you are still doing! We have immense faith that through your endeavours justice will prevail and will finally be seen to be done. I hope this letter will help inform the crucial and important work you are continuing to do to bring about the right and just outcomes in as timely a manner as possible for every single person in this community.

Sending warm regards and thanks to you and to the Inquiry team,

Christina

Christina Burgess

Director

HBDCA