

Sir Brian Langstaff  
Infected Blood Inquiry  
Fleetbank House  
1st Floor  
2-6 Salisbury Square  
London  
EC4Y 8AE

14th December 2020

Dear Sir Brian Langstaff & Team

### **Governments' responses to the infected blood scandal which they caused**

This letter is written to seek clarity, preferably in the form of a 'letter of intent' or 'letter of comfort', to reassure our members in relation to specific concerns they have highlighted, both formally and informally, and in particular during our recent AGM. The matters we are seeking to raise relate to the broad topic of the support provided, or not provided, by Government in response to addressing and alleviating the numerous impacts on those individuals and families infected and affected by contaminated NHS blood and blood products.

We consider these State responses to involve a broad concept of what constitutes 'Government' to include all UK Governments in power during the key timeframes for the Inquiry, as well as the devolved Parliaments or Assemblies, Local Authorities (i.e., as social care providers), various statutory agencies and 'arms-length' bodies. For example, one particular issue of interest at this time, is the way the Inquiry will investigate, analyse the impact of, and make recommendations about, the full range of support issues covering the overwhelming and highly stressful circumstances experienced during end-of-life care and the period following a bereavement. Our view is there should be a specific reference to palliative care in the List of Issues, and this recognition should extend to the other areas for targeted Inquiry investigation mentioned in this letter.

It is our expectation that when it comes to the Inquiry dealing with the various Governmental responses to supporting people, we consider these to be much more than simply an investigation and analysis of the various 'Schemes' which have been set up. Our understanding and expectations are for the Inquiry to investigate the full range of Government responses and support provision, including but not limited to:

- 'Support' as a factor of the services provided by NHS healthcare organisations to individual infected people and their families, to contact, inform, treat, equip and mitigate all relevant health and wellbeing issues as far as possible; including the adequacy or otherwise of this support (this being an overarching and substantive matter for the Inquiry)
- 'Support' as delivered by social care providers to individual infected people and their families, to meet needs including aids and adaptations in the home, support to carers, access to respite, benefit

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advice, palliative care, and other related issues; including the adequacy or otherwise of this form of statutory support

- 'Support' provided by the various 'ex gratia' and discretionary grant payment Schemes; including the adequacy or otherwise of this form of support (this being another substantive matter for the Inquiry)
- 'Support' provided by state welfare benefits; including the adequacy or otherwise of this form of support
- 'Support' provided in the form of grants and other resources to patient representative and advocacy organisations to allow them to engage collectively with Government on the issue of the NHS Contaminated Blood Scandal; including the adequacy or otherwise of this form of support
- 'Support' provided to, or rationale for not supporting, calls for public inquiries from campaigners, patient groups and other advocates; including the adequacy or otherwise of these responses
- 'Support' provided to, or rationale for not supporting, calls for action based on relevant issues raised by Parliamentary Committees or similar bodies; including the adequacy or otherwise of these responses
- 'Support' provided to, or rationale for not supporting, previous Inquiry activities, in particular the Independent Archer Inquiry (non-participation and blocking actions) and the Penrose Inquiry (Terms of Reference, appointment of Chair, discriminatory use of executive powers, extended delays, scantiness of resulting recommendation); including the adequacy or otherwise of these responses
- Any other response (or non-response) that can be classed as a form of Government 'support', or would have been, whether provided or not.

Our unique prior experience in relation to the Scotland-only Penrose Inquiry includes being involved in creating the Terms of Reference for that Inquiry. The guidance that officials gave us at the time was to keep the Terms of Reference brief and non-specific. The justification for this advice was it would allow a more open-ended process so that if issues arose which had not been anticipated but were considered significant, they would not be excluded by ToR which were too proscriptive. However, it soon became clear how the process had been manipulated by Health officials. The second choice Chair, Lord Penrose, used the lack of specificity in the ToR to exclude as much as he could; the opposite of what we had been led to expect. So rather than having greater flexibility, those broad ToR became a barrier to the fullness and legitimacy of the investigative process, and thus the final report and recommendations.

We recall discussing the issue of general or specific Terms of Reference during the period when you as the newly appointed Chair of the Infected Blood Inquiry and some of your equally newly appointed team travelled round to meet people and representative organisations. While in Scotland, the issue of having been 'conned' by the officials when the Penrose ToR were being drafted was raised. It was pleasingly positive to see the process you set up to ensure all the relevant terms and issues were included. Indeed, the List of Issues specifically allows for items to be added or expanded during the life of the Inquiry. It is our hope to see this flexibility option being applied towards broadening the List of Issues to cover the matters raised herein.

By way of your response, our hope is to receive confirmation or clarification on the following matters:

- To confirm the Inquiry's interpretation of 'Government' to include more than simply the UK Government at Westminster
- To confirm the Inquiry's interpretation of 'support' to include more than simply the current and previous Schemes
- To confirm the Inquiry's intention to re-draft the List of Issues to specifically include palliative care

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- ☑ To confirm the Inquiry's intention to re-draft the List of Issues to specifically include support for non-spousal family carers (i.e. parents and adult children as carers)
- ☑ To confirm the Inquiry's intention to re-draft the List of Issues to specifically include welfare benefit arrangements
- ☑ To confirm the Inquiry's intention to re-draft the List of Issues to specifically include support for advocacy and representative organisations
- ☑ To confirm the Inquiry's intention to re-draft the List of Issues to specifically include responses to various calls for independent investigations including a Public Inquiry
- ☑ To confirm the Inquiry's intention to re-draft the List of Issues to specifically include responses to issues raised in congressional settings, such as Parliamentary Committees
- ☑ To confirm the Inquiry's intention to re-draft the List of Issues to specifically include Governmental responses related to the Archer Inquiry and the Penrose Inquiry
- ☑ To provide in response a 'letter of intent' (or 'letter of comfort') to be shared with our members which will set out the Inquiry's agreement or otherwise with our interpretation, and indicating the anticipated process and timeframe to add to the List of Issues as detailed in this letter.

We continue to follow the Inquiry with intense interest, and thank you in anticipation of your response.

Yours sincerely,  
For and on behalf of the Scottish Infected Blood Forum,



Catherine Joyce Donnelly  
Convener