



20 May 2024

Dear Member

The Infected Blood Inquiry's final report represents a huge milestone in the long fight for truth and justice by the haemophilia and bleeding disorders community.

The contaminated blood scandal has cast a deep shadow over our community, affecting multiple generations over many decades. Today, we hope, those clouds are starting to lift.

Sir Brian Langstaff, chair of the inquiry, has identified failings across government, blood services and the medical profession that contributed to the catastrophic infections which continue to have a devastating impact on our community today. Lessons must be learnt to ensure this can never happen again.

In addition, Sir Brian has concluded that the Haemophilia Society was at fault in relation to some of its actions at the time.

Although Sir Brian acknowledged that the Haemophilia Society acted with good intentions, he concluded that our charity was too slow to react to the risks of AIDS, placed too much reliance on the advice of haemophilia clinician Professor Arthur Bloom and failed to encourage members to decrease their use of factor concentrate. Sir Brian also finds that the Haemophilia Society downplayed the significance of hepatitis C in the early 1990s.

We accept all Sir Brian's findings and are very grateful to have had the opportunity to play a full and active role in this inquiry.

On this historic day, it is important that we step forward to acknowledge and learn from the inquiry's findings about the actions of the Haemophilia Society in the 1970s, 80s and 90s.

In 2017, prior to the inquiry being announced, the Haemophilia Society issued an apology to the community.

In hindsight, this apology could and should have been issued sooner. We are sorry for any further distress this may have caused. We know that, for some, an apology will



never be enough, and it is a matter of deep distress to our charity to be linked in any way with the suffering of our community.

Clive Smith, Chair of the Board of Trustees, and who also has severe haemophilia A, today says to our community:

'We are very sorry for the hurt and anger which resulted from our advice and the breakdown of trust that followed. We cannot undo the decisions of the past, but we hope our actions throughout the inquiry and going forward demonstrate our determination to understand and learn from what happened.'

The Haemophilia Society has occupied a unique position within the inquiry as core participants. In addition to the scrutiny of our actions of the past, we have also advocated on behalf of our members and the wider community, to ensure the inquiry has been as thorough and far reaching as possible. Staff and trustees have been ever present at hearings to listen to evidence and support our members. At the outset of the inquiry, the Board of Trustees took a decision to allocate a legacy kindly left to us by one of our members to fund our work on the inquiry.

We have been as open and transparent as possible with the inquiry, with former staff members and trustees giving evidence, both verbally and in writing, and we submitted every relevant document in our possession, more than 20,000 scanned pages, including items which we weren't legally obliged to reveal.

We dedicated significant resources to our Public Inquiry Team, which was created to support our infected and affected members. Our team has helped many members access support payments and interim compensation as well as provided detailed updates on inquiry evidence and relevant political developments.

Many changes have already taken place. For example, although we continue to believe that our Board of Trustees should be predominantly made up of people with a direct personal connection to a bleeding disorder, we now have representatives covering a wide range of bleeding disorders from across the UK. We have also put measures in place to ensure greater objectivity and have built more challenge into our decision-making process.

For example, we have changed the way in which we check medical information and advice. In 1983 our reliance on the advice of a small number of well-respected haemophilia clinicians proved fatally misplaced. Our Medical and Scientific Advisory Group is made up of a wide range of clinical experts, including a physiotherapist, consultant, lead nurse and specialist dentist. Under no circumstances will we ever give out medical information without the signoff of a majority of members of this group.

Today we are a larger and better resourced charity than in the 1980s, but, in some respects, the challenges remain the same. With an increasing number of new treatments for haemophilia and other bleeding disorders on the horizon, the need for vigilance and challenge has never been greater. We are confident that our charity now



has improved capacity and the objectivity to ask the right questions of the right people to help to ensure that you, our members, have the information you need to make decisions about what treatment is right for you.

In his report today, Sir Brian acknowledges the importance of what we do by recommending that the Haemophilia Society should receive funding for our advocacy work.

In accepting Sir Brian's findings, we must also acknowledge that our staff and trustees in the 1980s and 90s faced exceptionally difficult circumstances. They worked hard and believed that they were doing the best they could for our members. We will never forget that at least half of our trustees in that period died as a result of contaminated blood, and others were bereaved or lost children. The current board of trustees has members both infected and affected by contaminated blood.

We know that you will want to consider Sir Brian's report carefully and will have questions about his findings and our response to them. We are holding a webinar on Wednesday 29 May at 7pm, which is open to all members, where we will be available to answer any questions.

A handwritten signature in black ink that reads "Kate Burt".

Kate Burt  
Chief Executive

A handwritten signature in black ink that reads "C. Smith".

Clive Smith  
Chair of the Board of Trustees

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