The Infected Blood Public Inquiry Newsletter

December 2022

The Haemophilia Society

Final few weeks of the Infected Blood Inquiry

The Infected Blood Inquiry has now finished taking oral evidence and there are just three weeks of hearings left. As the New Year approaches, we can finally look ahead to the end of the inquiry and the publication of its final report which is expected in Summer 2023.

All that remains is for lawyers to present their clients' conclusions based on all the evidence heard in hearings which run from 17 January to 3 February 2023. The Haemophilia Society's counsel, Katie Gollop KC, will make our presentation on 19 January and there will be representations on behalf of organisations including the Department of Health and Social Care, the United Kingdom Haemophilia Centre Doctors' Organisation, NHS Blood and Transplant, the Treloar's Trust, and health bodies from the devolved nations.

Then, Sir Brian Langstaff, Chair of the inquiry, will write his final report and recommendations.

Since September, the inquiry has heard from a variety of witnesses in the final stage of evidence hearings.

There was a focus on record-keeping in government and in hospitals as well as decision-making across the UK devolved governments.

Keeping his promise that those infected and affected would be at the heart of the inquiry, Sir Brian ensured that we heard from those directly impacted once more. There was heart-breaking evidence from mothers whose children were infected while being treated at Alder Hey Hospital and Birmingham Children's Hospital.

Others described on-going problems of receiving support from the Skipton Fund due to missing medical records and there was also evidence from people from minority ethnic communities.

The final two weeks brought the inquiry right up to date, with evidence from a range of organisations including the UK Health Security Agency, the General Medical Council and the Medicines and other regulatory bodies. For this section, Sir Brian was interested in hearing how current systems work which will guide his recommendations on future improvements.

Concluding the evidence stage, Sir Brian thanked all participants for their 'impressive' support. He said: 'It's a tribute to the sense of community, resilience and patience that you have continued individually and collectively to support one another and to give this inquiry the support it needs to complete its task. Thank you.'

Kate Burt, our Chief Executive, and Clive Smith, our Chair, pictured above, were present at the last day of evidence at the inquiry. Kate said: 'This has been another busy and important year at the inquiry, with crucial questions about accountability, openness and decision-making explored in some detail. As evidence now draws to a close, we know this will be an anxious time for many as we wait to hear what the final report will contain. I am thankful to all those who have had the courage to contribute to the inquiry process and to those who were able to attend to support those giving evidence.'

Contact our Public Inquiry Team on **020 7939 0780** or email **publicinquiry@haemophilia.org.uk**
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Government backtracks on compensation pledge

The government faced fierce criticism from campaigners and MPs after a junior minister told a parliamentary debate that it would not comment on a potential framework for compensation until after the Infected Blood Inquiry has published its final report.

Alex Burghart, a junior minister in the Cabinet Office, was responding to a debate in Westminster Hall in November on the Infected Blood Inquiry and compensation framework which was initiated by the All-Party Group on Contaminated Blood and Haemophilia, whose co-chairs are Dame Diana Johnson MP and Sir Peter Bottomley MP.

Despite a promise by the former Paymaster General, Michael Ellis MP in April that the government would publish its response to the compensation study carried out by Sir Robert Francis KC at the same time as his study was published, this has not happened. Mr Burghart said work was going on behind the scenes, but the government would now wait until the end of the inquiry before responding further. Campaigners pictured below were present to listen to the debate.

> **‘We are concerned that any delay now will mean people infected and affected will have to wait longer for full compensation.’**

Although the government paid interim compensation to all those infected and affected currently registered on a UK support scheme, there are many people who have been left out, such as bereaved parents, children and unpaid carers.

By not publishing its views on Sir Robert’s detailed compensation study, the government has left everyone who believes they might be entitled to full compensation in the dark as to whether they are eligible as well as how and when it might be paid. We are also concerned that any delay now will mean people infected and affected will have to wait longer for full compensation.

As we were about to send this newsletter the government announced it had set up working groups overseen by senior civil servants in order to prepare a compensation framework ready to be implemented ‘swiftly’ once Sir Brian makes his final report. Sir Robert Francis KC will provide ‘independent and transparent’ advice to these groups. Minister Jeremy Quin said the government accepted the ‘moral case’ for compensation.

The Infected Blood Public Inquiry Newsletter
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Government urged to do more on compensation

We have written to the government urging it to meet with campaigners to agree a framework for paying full compensation to those infected and affected.

On 2 December Kate Burt, our Chief Executive, and Clive Smith, our Chair, wrote to the Paymaster General Jeremy Quin, the minister with responsibility for the Infected Blood Inquiry, calling for an end to delays over revealing the government's plans for the payment of compensation.

Last year, former Health Secretary Matt Hancock told the inquiry that compensation would be paid if it was recommended by its Chair, Sir Brian Langstaff, and former Paymaster General Penny Mordaunt believed compensation was 'inevitable'. But despite this, the government appears reluctant to set up a framework for payment before the inquiry publishes its final report. We believe work needs to start now to have a workable system in place when the inquiry's recommendations are made public.

In their letter, Kate and Clive wrote: 'Compensation will never make up for the death of a beloved family member, nor, for the infected, the loss of what was once a bright future, but it does offer governmental recognition of the suffering caused, which is why the current impasse is so painful for those still waiting for that acknowledgement.'

You can read our full letter to Mr Quin on our website, in the public inquiry section.

Psychological support

For many, the end of the Infected Blood Inquiry will be a welcome relief, but for others who follow it closely, it will leave a gap which may be difficult to fill.

Although the inquiry has shone a welcome spotlight on the contaminated blood scandal, it has taken a significant toll on those who have provided oral and written statements and listened to the harrowing evidence. The inquiry hearings have also opened conversations with younger generations, who may also be struggling to deal with new information about their family history.

Psychological support that has been offered by the British Red Cross throughout the inquiry will be available until the final report is published and support is also available through the four UK infected blood support schemes. Family members of those infected can also access these services.

Contact the Red Cross on 0800 458 9473 or 020 3417 0280.

For support in Northern Ireland call 028 9615 5867, Scotland: 0131 242 1270, Wales: 029 20196141 and England: 0300 3301294.

The Terrence Higgins Trust also offers counselling sessions for former Macfarlane Trust beneficiaries and their families. Call 0808 802 0088 for more details.

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December 2022

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Remembering Nigel Pegram

We were very sorry to hear of the recent death of Nigel Pegram, 66, a long standing and active member of the Haemophilia Society.

Nigel, who had haemophilia B, will be remembered for his kindness and generosity by so many in our community. He devoted a lot of time to helping our members with benefit applications and provided invaluable guidance on applying for mobility and attendance allowances. Always very generous with his expertise and time, Nigel took part in numerous working groups, dating back to the late 1980s when he was part of a group which looked into the quality of treatment and care for people with bleeding disorders in the UK.

We send our deepest condolences to Nigel's son and family.

New child support payment in Wales

Children of people infected with hepatitis C and HIV as a result of treatment with contaminated blood and blood products in Wales are to receive a support payment.
The Welsh government has announced that from January 2023 an annual payment will be made to young people up to the age of 18, or 21 if in full time education, who are either the biological children of someone registered with the Wales Infected Blood Support Scheme (WIBSS) or live in the same household.

In recognition of the 'significant impact' the contaminated blood scandal has had on their lives, a payment of £3,000 a year for the first child and £1,200 for the second and subsequent children has been agreed.

This is the first scheme of its kind in the UK. Although the England Infected Blood Support Scheme has a child supplement payment, this is means-tested. There is no dedicated child support payment available through the schemes in Scotland and Northern Ireland at present.

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Our final document has been submitted – thanks to you

We have just handed in a key document to the Infected Blood Inquiry which focuses on the all-important final report and recommendations.

Like all core participants, we had the opportunity to tell Sir Brian Langstaff, Chair of the inquiry, what recommendations and findings of fact we think he should make. Our 'final submissions' document focused on what changes could be made to improve safety, treatment and care for people with bleeding disorders, as well as looking back on key areas that went wrong. We also considered all the evidence heard about the role of the Haemophilia Society and responded to the points raised. The document should be published on the inquiry's website early in 2023.

Over the last year, we've organised three major surveys, held webinars and had many individual conversations with you, our members, to ensure that our final submission reflects your views. More than 600 people responded to our surveys on compensation, non-financial compensation and, most recently, on issues relating to actions of the past.

Thank you to everyone who has taken the time to comment on these crucial issues.

Our last survey, sent out in October, helped us to highlight what areas to focus on when we were considering the actions of the past, which made up a relatively small section of the overall document. We had 62 responses from members, of which 12% were infected as well as affected, 50% affected and 38% infected.

The survey found that your top priority was to address the response of government, followed by candour and cover-up, viral inactivation, treatment and support, self-sufficiency in blood, stigma and decision-making in medical advisory committees. Any suggested findings submitted on these issues must be based on evidence heard by the inquiry.

Our aim, in partnership with our legal representatives Eversheds Sutherland, was to use the evidence given to the inquiry to focus on the key issues of importance to improving the lives of people with bleeding disorders in the future as well as ensuring that mistakes from the past cannot be repeated.