

The Infected Blood Public Inquiry Newsletter

August 2022

The
Haemophilia
Society

Interim compensation of £100,000 announced

The government will pay interim compensation of £100,000 to anyone currently registered on a UK infected blood support scheme, it announced last week. The issue of compensation has dominated the Infected Blood Inquiry in recent weeks, resulting in its Chair, Sir Brian Langstaff, pictured right, making an interim recommendation at the end of July that the government should pay interim compensation to this group 'without delay'.

Last week the government announced that it would implement Sir Brian's recommendation in full which means those infected and bereaved partners who are registered on a scheme will receive £100,000. Payment will be made by the end of October through the existing support schemes which will contact recipients directly. The money will be tax-free and will not affect any benefits that an individual might receive.

Kate Burt, Chief Executive of the Haemophilia Society (THS), said: 'This is the first time a UK government has paid compensation for infection and suffering caused by the contaminated blood scandal. While welcoming this news, there is still a long way to go in ensuring that all those who have endured devastating loss and suffering – such as bereaved parents and children – are recognised and compensated.'

'Steps must be taken now to set up a workable scheme which can deliver full compensation quickly and fairly.'

The announcement comes after months of pressure. Our chair, Clive Smith, pictured at 10 Downing Street in July, was part of a joint delegation of campaign

groups and politicians who handed in a letter to the Prime Minister demanding that interim compensation be paid.

In June, the government published a report it commissioned by Sir Robert Francis QC which looked at a framework for compensation. In his report, Sir Robert said there was a 'compelling case' for interim compensation to be paid to the infected. We continue to wait for the government's official response to this report.



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Kate Burt, Chief Executive

While this announcement is very good news, we know that many of you who have suffered terrible loss are not included in this interim payment, which will cause understandable upset and hurt. We hope this marks the start of the compensation process and if you are not eligible this does not mean you won't qualify for compensation at the end of the inquiry.

The Haemophilia Society will continue to push for a framework to be put in place as soon as possible to speed up the compensation process once Sir Brian makes his final report in mid-2023. In his evidence to the inquiry, Sir Robert recommended that expert medical and legal panels be set up in advance to establish agreed criterion for financial tariffs and medical conditions. We also want the government to look at changes to the law so that estates are not subject to Inheritance Tax when compensation is awarded.



Contact our Public Inquiry Team on **020 7939 0780** or email publicinquiry@haemophilia.org.uk
Follow us on Twitter [@HaemoSocUK_PI](https://twitter.com/HaemoSocUK_PI) or join our dedicated
public inquiry Facebook group at www.facebook.com/groups/HSInquiry

Are you eligible for payment?

Over the last few weeks we have received a number of calls from members who were unaware they qualified for payments under the infected blood support schemes in England, Wales, Northern Ireland and Scotland.

You are eligible for ongoing support payments if any of the below are the case:

- you were infected with hepatitis C through treatment with contaminated blood products for longer than six months (termed a 'chronic' infection by the support schemes) even if you later cleared the virus through treatment. You will need documentation to prove a chronic infection, particularly if you self-cleared the virus
- you received a payment from the Skipton Fund for your infection
- you are the bereaved partner, widow or widower of someone infected with hepatitis C, as detailed above, or HIV
- you were infected with HIV through treatment with contaminated blood products or through a partner who was infected through this route
- you were chronically infected with hepatitis C and were infected by someone who was infected through treatment with contaminated blood products. This may have been through sexual transmission, accidental needlestick injury or from mother to baby.

Some new or increased lump sum payments may also be payable to the estates of infected people who have died.

One of our members, Dean King, pictured below, was infected with hepatitis C as a child in the 1980s through treatment for his severe haemophilia B. His family received a payment from the Skipton Fund in 2004, and he went on to clear the virus after treatment. He only found out this month that he was eligible for payments from the England Infected Blood Support Scheme (EIBSS).

Dean said: 'I was shocked and angry when I discovered that I should have been registered with EIBSS, but I am more concerned that I could be one of many who are missing out. There are others in a much worse position than me who may be desperate for this kind of benefit.'



How to apply

If you think you are eligible, first phone your relevant UK support scheme – payments are made according to where you were infected, not where you live.

England Infected Blood Support Scheme:
0300 330 1294

Wales Infected Blood Support Scheme:
0292 0902280

Scotland Infected Blood Support Scheme:
0131 2756754

Infected Blood Payment Scheme
for Northern Ireland: **028 9536 3817**

If you or your partner were registered with any of the Alliance House schemes – the Macfarlane Trust, the Skipton Fund, the Caxton Foundation or the Eileen Trust – you will be advised to contact Russell-Cooke, the firm of solicitors which now holds the paperwork from those organisations. The person dealing with previous records is Julie

Collingham who is
on **0208 7899111** or **Julie.**

collingham@russell-cooke.co.uk. The documents will then be sent directly to the support scheme, which currently takes between four and seven weeks. You will be contacted again once the documents have arrived to discuss what payments you will receive.

Please contact our Public Inquiry Team with any specific questions.

NEWS IN BRIEF

Support group for bereaved parents

Rosemary Calder, whose son Nicky died as a result of the contaminated blood scandal, has set up the Tainted Blood Bereaved Parent Support Group and is keen to hear from anyone who'd like to join.

Rosemary, who is pictured below with Nicky, said: "Our group is for bereaved parents in the UK who have lost children as the result of them receiving contaminated blood or blood products. It's somewhere that we hope you can find comfort and support and where you can share your experiences with other parents who have travelled the same journey. It's also a place for us to be able to talk about our lost children and share our precious memories."

You can find the group using this link: <https://www.facebook.com/groups/1135170780619639/> or you can call Rosemary on 07961 912285.



Northern Ireland rolls out enhanced stage 1 payments

Northern Ireland's Department of Health (DoH) has announced it will be implementing HCV stage 1 (enhanced) payments for people infected with hepatitis C, which will bring it broadly in line with the schemes in England, Wales and Scotland. The announcement comes after a lengthy consultation process which included the Haemophilia Society who, along with others, participated in the working group on the issue.

This payment is aimed at those stage 1 recipients who suffer symptoms which have a significant adverse impact on their ability to carry out every day activities, either mentally or physically. Like Scotland and Wales, this will be self-assessed. However, a supporting declaration by a medical professional will be required to determine so far as is possible a link to HCV infection and/or treatment.

Details of the new payment and how to apply were emailed to recipients of the Infected Blood Payment Scheme for Northern Ireland last week in August.

Hepatic encephalopathy

We've been asked by one of our members, Justine Gordon-Smith, to highlight the condition of hepatic encephalopathy, which can result from chronic hepatitis C infection.

Hepatic encephalopathy, which is treatable, is caused when toxins that are normally cleared from the body by the liver accumulate in the blood, eventually traveling to the brain. This happens because of the damage sustained to the liver as a result of hepatitis C infection. Early symptoms include forgetfulness, personality or mood changes and worsening handwriting which can progress to unusual movements, seizures, jumbled or slurred speech and confusion.

Justine's father Peter, who died four years ago, developed the condition following a diagnosis of liver cancer as a result of hepatitis C, but their family only realised he had hepatic encephalopathy after his death. Justine said: 'I don't want anyone to suffer the way we did. When we told doctors about Dad's symptoms they just looked at us blankly. Not having a diagnosis and therefore treatment deprived him of having a dignified end of life with his loved ones. I would urge any family in a similar position to demand to see a specialist hepatologist.'

To find out more about hepatic encephalopathy, contact the Hepatitis C Trust or the British Liver Trust.

Inquiry evidence nears end

The inquiry, which resumes on 12 September, is now entering the final stages of evidence and will hear from politicians, civil servants and panels of those infected and affected in the next few months.

But having hoped to finish all oral evidence by the end of the year, the inquiry has pushed back the deadline for submissions from legal representatives until December, meaning that their final presentations won't be made until January 2023. Sir Brian Langstaff, Inquiry Chair, is expected to publish his final report in mid-2023.

This year, the inquiry has focused on detailed scientific information about blood fractionation and the UK's two plants at Elstree and Edinburgh. It has questioned why BPL Elstree was slow to redevelop – this did not happen until the early 1980s – and why PFC Edinburgh never worked to full capacity, despite being designed as a round-the-clock operation. The inquiry looked at the UK's efforts to be 'self-sufficient' in blood products, meaning that demand was met using products made from donors in the UK, rather than having to import products. Initial estimates of what it would take to achieve self-sufficiency proved conservative and as demand grew, the goals changed, meaning supplies in England and Wales constantly fell short. Scotland, which also supplied Northern Ireland from the early 1980s did achieve self-sufficiency.

A number of senior politicians have also given evidence, including former Prime Minister John Major, and former health secretaries William Waldegrave, Virginia Bottomley, Jeremy Hunt, John Reid, Alan Milburn and Andy Burnham, pictured. Mr Burnham argued that the Crown Prosecution Service

should consider charges of corporate manslaughter and said the Department of Health had been 'grossly negligent of the safety of people in the haemophilia community over five decades'.

Mr Reid described how he overturned 25 years of government opposition to financial support for people infected

with hepatitis C within weeks of taking office in 2003. He said: 'If the line's wrong, change the line.'

Much of the evidence has looked at the role of civil servants, and a number have appeared as witnesses. The inquiry has looked at the issue of 'group think' and whether the government's position on contaminated blood became entrenched because it wasn't challenged sufficiently by either ministers or civil servants. Evidence from civil servant Rowena Jecock highlighted a briefing note she'd written for ministers following the Archer Inquiry in March 2009 which contained government 'lines' which were virtually unchanged in 20 years, including the much-used phrase that treatment for haemophilia using blood products was 'the best available at the time'.

The inquiry will now consider whether it needs to call any further evidence, based on submissions from core participants, including the Haemophilia Society, about what Sir Brian should include in his final report.

You can find the inquiry's latest timetable on its website: www.infectedbloodinquiry.org.uk.

