

DEBATE PACK

Number CBP 2016/0077, 7 April 2016

Reform of support arrangements for people infected with contaminated blood

This pack has been prepared ahead of the debate in the Commons Chamber on Tuesday 12 April 2016 on **reform of support arrangements for people infected with contaminated blood.**

The subject for the debate has been nominated by the Backbench Business Committee and the motion is

"That this House recognises that the contaminated blood scandal was one of the biggest treatment disasters in the history of the NHS, which devastated thousands of lives; notes that for those affected this tragedy continues to have a profound effect on their lives which has rarely been properly recognised; welcomes the Government's decision to conduct a consultation to reform support arrangements and to commit extra resources to support those affected; further notes, however, that the current Government proposals will leave some people worse off and continue the situation where some of those affected receive no ongoing support; and calls on the Government to take note of all the responses to the consultation and to heed the recommendations of the All Party Parliamentary Group on Haemophilia and Contaminated Blood's Inquiry into the current support arrangements so as to ensure that no-one is worse off, left destitute or applying for individual payments as a result of the proposed changes and that everyone affected by the tragedy, including widows and dependents, receives support commensurate with the decades of suffering and loss of amenity they have experienced."

The House of Commons Library prepares a briefing in hard copy and/or online for most non-legislative debates in the Chamber and Westminster Hall other than half-hour debates. Debate Packs are produced quickly after the announcement of parliamentary business. They are intended to provide a summary or overview of the issue being debated and identify relevant briefings and useful documents, including press and parliamentary material. More detailed briefing can be prepared for Members on request to the Library.

Dr Sarah Barber

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1. Library briefing

1.1 Background

During the 1970s and early 1980s thousands of UK patients contracted HIV, Hepatitis C, or both, from contaminated blood or blood products. A recent response to a Parliamentary question from the Under-Secretary of State for Health provided some 2011 estimates of how many people had been infected:

The Review of the Support Available to Individuals Infected with Hepatitis C and/or HIV by NHS-supplied Blood Transfusions or Blood Products and their Dependants, which this Government published in January 2011, included estimates that around 1,300 individuals had been infected with HIV through treatment with National Health Service-supplied blood or blood products, of whom approximately 400 remained alive at the end of 2010. Similarly, it is estimated that around 33,000 individuals may have been infected with hepatitis C, of whom it is estimated that approximately 9,000 remained alive in 2003. The Department does not hold information on the cause of death; however, it is likely that many of those infected with hepatitis C will have died of unrelated causes.¹

No-fault Government payment schemes were established to provide support for those affected.

Despite two internal Department of Health inquiries, establishment of three bodies to administer payments to those infected, and reassurances that all possible steps were taken to avoid infections, there has been continuing debate over several issues relating to contaminated blood, including:

- the circumstances under which users of blood products became infected, and whether this could have been prevented;
- refusal by successive Governments to hold a public inquiry; and
- financial support for those infected.

These concerns eventually led to the establishment of the Independent Public Inquiry into Contaminated Blood and Blood Products (the Archer Inquiry), a non-statutory inquiry which reported in February 2009.² Amongst the Archer Inquiry recommendations was a call for reform of support for those affected in line with a compensation scheme in place in the Republic of Ireland for those affected by infected blood products which offers higher payments than those in the UK. Successive Governments have rejected comparability with the Irish scheme on the basis that it was established to compensate victims for wrongdoing by a government agency but that no similar wrongdoing occurred in the UK.

¹ Blood: Contamination:Written guestion - 220665 16 January 2015

The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009

The <u>Labour Government's response to the Archer Inquiry</u> included:

- increasing annual payments for people infected with HIV to £12,800, replacing the previous variable payments (averaging £6.400)
- the Haemophilia Society to receive £100,000 per year for the next five years
- a review of financial relief for people affected by hepatitis C to be taken in five years.3

An April 2010 Judicial review of the previous Labour Government's response to the Archer Inquiry questioned the basis for rejecting comparability with Ireland⁴ and the coalition Government responded with a proposal to review aspects of financial support, while restating its rejection of the Irish model.

On 10 January 2011 the coalition Government announced the results of the review which included proposals to:

- reform payments to those infected with Hepatitis C who have developed advanced liver disease, increasing the lump sum from £25,000 to £50,000, introducing an annual payment of £12,800, and establishing a discretionary fund to provide additional hardship payments
- remove a provision preventing payments for Hepatitis C patients deceased before 29 August 2003, allowing new claims in these cases to be made until the end of March 2011
- provide free prescriptions and counselling for those with Hepatitis C and/or HIV. 5

These measures, introduced in 2011 across the UK, were estimated to represent an additional £100-130m of support over the life of the 2010-2015 Parliament.6

They were welcomed as a step in the right direction by some patient and campaign groups, there has been continuing concern that the level of payments still falls below that in the Republic of Ireland and that a number of those affected by Hepatitis C will not be eligible for the increased payments.

The Penrose Inquiry was set up in Scotland in 2008 to investigate cases of patients with hepatitis C and HIV following the use of infected blood products. The final report was published in March 2015.

Following the publication of the report, and in response to ongoing concerns about the current financial support system, the Secretary of State for Health announced in March 2015 that the Government would look at a new financial system and a transitional payment of £25 million would be provided. A consultation on proposals for a new financial support scheme was published in January 2016. The current financial

Department of Health, Government response to Lord Archer's Independent report on NHS supplied contaminated blood and blood products, 20 May 2009.

March, R v Secretary of State for Health [2010] EWHC 765 (Admin)

⁵ Department of Health, *Review of the support available to individuals infected with* Hepatitis C and/or HIV by NHS supplied blood transfusions or blood products and their dependants, 10 January 2011

HC Deb 10 January 2011, c1232

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support system applies across the UK but in March 2016, the Scottish Government announced that they will be setting up a new separate financial support scheme.

More information is provided below about the current support system, the Penrose Inquiry and recent developments in this area.

1.2 Current financial support system

Support for patients with HIV or Hepatitis C as a result of infected blood products is provided by a number of trusts and charities.

A table within the Government consultation document on a new financial support scheme provides an overview of the different organisations and the types of support currently available:

Figure 1. Table of current payment schemes⁷

Organisation	Year set up	Status of organisation		Types of support available
MFET Ltd	2010	Non- discretionary company limited by guarantee		Variable lump sum on entry Annual payments (£14,749 in 2015/16) Reimbursement for Prescription Pre- payment Certificate
Macfarlane Trust	1988	Discretionary charity	disorders infected with HIV (including those co- infected with hepatitis C) and their families, including bereaved family members and	Means-tested income topups One-off grants Means-tested winter payments Other support, including benefits advice
Eileen Trust	1993	Discretionary charity	infected with hepatitis C) through blood transfusion and their families, including bereaved family members and	Means-tested regular payments One-off grants Winter payments Beneficiary events Other support, including benefits advice

Department of Health, <u>Infected blood: reform of financial and other support</u>, 21 January 2016

Skipton Fund Ltd	Non- discretionary company limited by guarantee	· '	Lump sum at stage 1 and stage 2
		Stage 1: chronic hepatitis C	Annual payments for stage 2 (£14,749 in 2015/16)
			Reimbursement for Prescription Pre- payment Certificate
Caxton Foundation	Discretionary charity	only hepatitis C and their families, including bereaved family members and dependents	Means-tested income topups One-off grants Winter payments Other support including benefits advice

The 2015 APPG on Haemophilia report, Inquiry into the current support for those affected by the contaminated blood scandal in the UK provides further information on these schemes and an appraisal of them. The APPG reported a number of concerns regarding the current system, these include a lack of awareness about the support available, a need for an improved structure and appeals process and concerns about the failure of current system to meet the needs of those affected.

The Under-Secretary of State for Health, acknowledged the APPG report and other concerns in responding to a debate on this subject in January 2015, but said that the Penrose Inquiry report should be taken into account when considering changes to the system.8

1.3 The Penrose Inquiry

The Penrose Inquiry was set up in Scotland under section 28 of the Inquiries Act 2005, as a judicially led review into the transmission of Hepatitis C and HIV from NHS blood and blood products.

The <u>final report</u> was published in March 2015 and consists of five volumes. Lord Penrose reported that whilst some commentators believe that more could have been done to prevent infection in certain groups, the evidence showed that there were few areas where matters could have been handled differently. However the report did note a delay with the introduction of the screening of blood for Hepatitis C. There was one recommendation within the report: that the Scottish Government takes all reasonable steps to offer a Hepatitis C test to everyone in Scotland who had a blood transfusion prior to 1991 and has not previously been tested.

The Prime Minister was asked about the Penrose inquiry report in PMQs on the day of its publication. He made an apology to all those affected

HC Deb 15 January 2015 c1072

by infected blood products and confirmed the decision to change the payment support system.⁹

Following the publication of the Penrose Inquiry report, a written statement from the Secretary of State for Health was published. It stated that the Government would allocate £25 million as a transitional payment and a new support system for these patients would be developed. The Minister stated that despite improvements to the financial systems in 2011, there had been ongoing criticism of the schemes. The challenge for the Government was to find the most appropriate way to provide financial assistance while ensuring any new system is responsive to medical advances and sustainable in financial terms:[....]

From listening to a range of views on the current system, it is apparent that there might be some people who are experiencing significant ill health which may result from their infection(s) who feel they are not well supported by the existing system. However, it is important to recognise there are elements of the current system which do find favour among the beneficiary community. The challenge for any future Government will be to identify the most appropriate way of targeting financial assistance, whilst ensuring that any system can be responsive to medical advances and is sustainable for Government in financial terms.

I thank both the hon. Member for North East Bedfordshire (Alistair Burt) and the APPG for their reports, both of which we are considering carefully. It is with frustration and sincere regret that our considerations on the design of a future system have been subject to postponement whilst we awaited publication of Lord Penrose's final report of his Inquiry in Scotland. We had hoped to consult during this Parliament on reforming the ex-gratia financial assistance schemes, considering, amongst other options, a system based on some form of individual assessment. However, I felt that it was important to consider fully Lord Penrose's report before any such consultation. Given its publication today, we clearly are not in a position to launch a consultation, on one of the last sitting days of this Parliament.

However, Lord Penrose's report has now been published. It can be found on the Inquiry website at:

http://www.penroseinquiry.org.uk/. Whilst it will be for the next Government to consider all of Lord Penrose's findings, I would hope and fully expect proposals for improving the current complex payment system to be brought forward, with other UK Health Departments.

In the meantime I am pleased to announce that I will be allocating up to an additional one-off £25 million from the Department of Health's 2015/16 budget allocation to support any transitional arrangements to a different payment system that might be necessary in responding fully to Lord Penrose's recommendations. We intend this to provide assurances to those affected by these tragic events that we have heard their concerns and are making provision to reform the system.

[...] 10

⁹ HC Deb 25 March 2015 c1423

Written statement: Infected Blood, 25 March 2015

There have been a number of responses to the publication of the Penrose Inquiry report. Campaign groups such as Tainted blood have expressed disappointment at the weakness of the recommendations in the report and have called for real compensation to be made available for the group of people affected by infected blood. 11 The Chief executive of the Hepatitis C Trust said the organisation were happy that the report provided some answers about the infections, but was disappointed that it did not make recommendations regarding financial support for those affected:

"We are pleased that the report has finally been published and has provided at least some answers to the questions of how and why this disaster unfolded. It is clear that more could and should have been done to prevent the infection of people with hepatitis C via contaminated blood, although this is perhaps of little comfort to those who have already lost loved ones. While we are happy with the recommendation to introduce screening of people who received blood transfusions pre-1991, we are disappointed that the report does not include any specific recommendations regarding the reform of the financial support system for victims of the tragedy." 12

1.4 Proposals for a new UK financial support system January 2016

On 17 July 2016, a Written Statement was made by the Parliamentary Under-Secretary of State for Health in the House of Lords. This statement said that the Government were considering how the financial support arrangements might be improved. While no decisions had been made yet, the £25 million will be used to support transitional arrangements and the Department will be consulting on how a new scheme might be structured.

Diana Johnson, Chair of the APPG on Haemophilia and Contaminated blood tabled an urgent Question about this issue on 20 July 2015. 13 She inquired about the support available for affected individuals. The Parliamentary Under-Secretary of State for Health, Ben Gummer confirmed that a public consultation would take place on a new support system and that the four UK Health departments had been working together on this matter.

In an oral statement to Parliament in January 2016, the Public Health Minister, Jane Ellison announced the launch of a public consultation on infected blood scheme reform.¹⁴ She said that the Department of Health had identified another £100 million for the proposals within the consultation and laid out the principles on which the consultation would be based:

[...]

Scheme reform is a priority for me and for this government, and for this reason I can announce today that the Department of

¹¹ Tainted Blood, <u>news: Press release</u>, 25 March 2015

¹² Hepatitis C Trust, The Hepatitis C Trust's Penrose Inquiry report response

¹³ HC Deb 20 July 2015 c1221

Department of Health, Infected blood scheme reform, 21 january 2016

Health has identified £100 million from its budget for the proposals set out in the consultation. This is in addition to the current spend and the £25 million already announced in March 2015. This will more than double our annual spend on the scheme over the next 5 years. This is significantly more than any previous government has been able to provide for those affected by this tragedy.

I know all too well of the ill health and other impacts on many of those affected by the tragedy of infected blood. I have corresponded with many of those affected, and their MPs; they each have their own story to tell. I have reflected carefully on all of this in developing the principles upon which the consultation is based. These are that:

- we focus on those who are infected
- we are able to respond to new advances in medicine
- we provide choice where possible
- we maintain annual payments to everyone currently receiving them

This <u>consultation</u> is an opportunity for all those who have been affected to have their say, and it's really important this extends to those quieter voices who we hear from less often.¹⁵

The Minister went on to highlight some of the key components of the proposed scheme and the consultation:

- All those with hepatitis c would be offered an individual health based needs assessment which would determine the level of annual payment received;
- Those currently receiving annual support would have their payments uplifted to £15,000 a year;
- The intention to introduce an opportunity to enhance access to hepatitis C treatment under the new scheme, especially for those who just fall short of current criteria;
- The consultation will include a choice of options for the bereavedcontinued access to discretionary support or a one off lump sum payment; and
- In light of concerns regarding the complex nature of the current five schemes, there is a proposal for one scheme run by one single body.

The consultation is open until 15 April 2016. More information is provided in the consultation document, <u>Infected blood: reform of financial and other support</u>.

The Haemophilia Society has responded to the Government consultation. They have said they are shocked and angry that the proposals in the document suggest that the majority of people will be worse off under a new scheme:

Following the long awaited launch of the government consultation 'Infected blood: reform of financial and other support', The Haemophilia Society is shocked and angry that the proposals suggest that the majority of people in our community who have been impacted by this terrible situation will be

Department of Health, Infected blood scheme reform, 21 january 2016

financially worse off in the new scheme, and will receive significantly lower income than their peers in Scotland, if the current proposal is accepted there. The Government's headline may be more resources, but the truth appears to be rather different. Many of the most disadvantaged people will lose out. We will be undertaking a full analysis, seeking legal advice and supporting our members to understand the implications of this proposal, enabling us to respond to the consultation with strong evidence.

It is important to stress these proposals are only a consultation and it is vital that the community's voice is heard. We will be briefing parliamentarians on the impact these proposals will have and will also be publishing materials to help our members have their say. We will be taking action at Westminster to ensure that our concerns our heard loud and clear. We hope that ministers will listen. 16

1.5 Proposals for a new financial support system in Scotland (March 2016)

The current financial support systems apply across the UK, but the Scottish Government have recently announced that they will be introducing a new financial support scheme for those affected by infected blood products.

An independent Scottish Financial Support Review group was established by the Scottish Health Secretary, Shona Robison, following the publication of the Penrose Inquiry report in 2015. This group, which included patient and family representatives, was asked to make recommendations on how to improve the level of support offered to people who contracted Hepatitis C and HIV through infected blood products. The group published its report in December 2015.

On 18 March 2016, the Scottish Government announced that it had accepted the key financial recommendations of the group and that financial support would be strengthened with an extra £20 million over the next three years:

Today the Scottish Government also confirmed a new Scottish scheme will be established for people who became infected with HIV and hepatitis C after treatment in Scotland, and their dependents. Current support packages for those affected by infected blood are delivered through UK-wide schemes.

The recommendations, which will be implemented in full in Scotland, are:

- Annual payments for those with HIV and advanced hepatitis C will be increased from £15,000 a year to £27,000 a year, to reflect average earnings
- Those with both HIV and hepatitis C will have annual payments increased from £30,000 to £37,000 to reflect additional health needs
- When a recipient dies, their spouse or civil partner will continue to receive 75 per cent of their annual payment
- Those infected with chronic hepatitis C will receive a £50,000

The Haemophilia Society, <u>Initial response to the contaminated blood consultation</u>. 22 January 2016

lump sum payment (previously £20,000), meaning an additional £30,000 for those who have already received the lower payment • A new Support and Assistance Grants scheme will be established in Scotland, to administer and provide more flexible grants to cover additional needs. Scottish Government funding for this scheme will be increased from £300,000 to £1 million per vear. 17

The Chair of the charity, Haemophilia Scotland welcomed the announcement. He said that it was a watershed moment for those involved in this campaign and that the Scottish approach stands in stark contrast with those south of the of the border.

"This announcement is a watershed moment for everyone involved in this long running campaign. There are three key elements of the announcement which are particularly welcome.

"Firstly, the increase in on-going support for those who are most unwell means that we can have some confidence that they will no longer be living in poverty as a result of their infections.

"Secondly, introducing pensions for widows and widowers is an important recognition that they suffered losses in their own right and that they should have a secure future.

"Thirdly, the upfront payment of an additional £30,000 to all those who will not receive on-going support goes some way towards recognising that everyone who has lived with these infections has suffered physically, mentally, or financially.

"No scheme can truly make up for the loss of life, and health, caused by this disaster. The Cabinet Secretary has acknowledged that there is more to be done once these schemes move to Scotland. However, today, we have made historic progress.

"This new, Scottish, approach stands in stark contrast to the deeply concerning proposals currently being consulted on south of the border." 18

Scottish Government, Extra £20 million for infected blood support, 18 March 2016

Scottish Government, Extra £20 million for infected blood support, 18 March 2016

2. News items

BBC Online

Call for swifter action to identify contaminated blood victims

Eleanor Bradford 21 March 2016

http://www.bbc.co.uk/news/uk-scotland-35856708

The Herald

Contaminated blood scandal financial package for Scots receives extra £20m

18 March 2016

http://www.heraldscotland.com/news/health/14354009.Contaminated blood scandal financial package for Scots receives extra

Guardian

Victims of contaminated blood scandal face major cut to payments from government

James Meikle 15 February 2016

http://www.theguardian.com/society/2016/feb/15/nhs-contaminatedblood-scandal-hiv-hepatitis-compensation-cut

BBC Online

Infected blood scandal: Government proposes more money for victims

21 January 2016

http://www.bbc.co.uk/news/health-35371248

Independent

Penrose report: Blood scandal inquiry branded a 'whitewash'

Charlie Cooper 25 March 2015

http://www.independent.co.uk/news/uk/home-news/penrose-reportblood-scandal-inquiry-branded-a-whitewash-10134095.html

BBC Online

Penrose inquiry: David Cameron apologises over infected blood 25 March 2015

http://www.bbc.co.uk/news/uk-scotland-32041715

3. Press releases

Scottish Government Extra £20 million for infected blood support 18 March 2016

Key recommendations of independent group accepted. Financial support for people affected by infected NHS blood and blood products will be strengthened with an extra £20 million investment over the next three years.

The announcement came as the Scottish Government accepted the key financial recommendations of the independent Financial Review group looking at the issue.

The group, involving patient and family representatives, was set up by Health Secretary Shona Robison following the Penrose Inquiry into infected NHS blood, which reported last year. The group was tasked with recommending how to improve the level of support on offer to people who contracted hepatitis C and HIV through infected NHS blood and blood products in the 1970s and 80s.

Today the Scottish Government also confirmed a new Scottish scheme will be established for people who became infected with HIV and hepatitis C after treatment in Scotland, and their dependents. Current support packages for those affected by infected blood are delivered through UK-wide schemes.

The recommendations, which will be implemented in full in Scotland,

- Annual payments for those with HIV and advanced hepatitis C will be increased from £15,000 a year to £27,000 a year, to reflect average earnings
- Those with both HIV and hepatitis C will have annual payments increased from £30,000 to £37,000 to reflect additional health needs
- When a recipient dies, their spouse or civil partner will continue to receive 75 per cent of their annual payment
- Those infected with chronic hepatitis C will receive a £50,000 lump sum payment (previously £20,000), meaning an additional £30,000 for those who have already received the lower payment
- A new Support and Assistance Grants scheme will be established in Scotland, to administer and provide more flexible grants to cover additional needs. Scottish Government funding for this scheme will be increased from £300,000 to £1 million per year

Ms Robison said:

"Infected blood is one of the most terrible chapters in the history of our NHS. Those affected have suffered dreadful impacts on their health, life expectancy and quality of life, including financial losses. It is guite right that they and their families are given adequate support to help them cope with consequences for which they are entirely blameless.

"We acknowledge that many people affected by this issue believe the financial support packages on offer do not reflect the impact of these infections, not just for them but also their families.

"With this in mind, I established a financial review group so patient groups and others could input into how the new reformed schemes will work. I am pleased today to be able to accept the key financial recommendations in full.

"This will mean a substantial package of additional financial support, recognising the hardships many face.

"I have today accepted the group's key financial recommendations, and we will move forwards on this basis. I am also clear that this is not the end of the process, and that there will be on-going work with the patient groups on this matter.

"We are now working with the UK Department of Health, and the existing UK-wide support schemes, to provide the additional financial support as soon as possible and manage a smooth transition to our new Scottish scheme."

Bill Wright, Chair of Haemophilia Scotland, said:

"This announcement is a watershed moment for everyone involved in this long running campaign. There are three key elements of the announcement which are particularly welcome.

"Firstly, the increase in on-going support for those who are most unwell means that we can have some confidence that they will no longer be living in poverty as a result of their infections.

"Secondly, introducing pensions for widows and widowers is an important recognition that they suffered losses in their own right and that they should have a secure future.

"Thirdly, the upfront payment of an additional £30,000 to all those who will not receive on-going support goes some way towards recognising that everyone who has lived with these infections has suffered physically, mentally, or financially.

"No scheme can truly make up for the loss of life, and health, caused by this disaster. The Cabinet Secretary has acknowledged that there is more to be done once these schemes move to Scotland. However, today, we have made historic progress.

"This new, Scottish, approach stands in stark contrast to the deeply concerning proposals currently being consulted on south of the border."

Background

Infected blood products infected thousands of people in hospitals and clinics across the world during the 1970s and 1980s. The whole of the UK's NHS was impacted.

An estimated £10.5 million will be made available in 2016/17 and 2017/18 and £6.5 million in the years after that. This compares with a current budget of £2.5 million each year – an additional £20 million over the first three years.

As recommended by the group, the Scottish Government will aim to deliver the new scheme through a single body so those affected no longer need to apply to more than one body for funding. In the interim, the Scottish Government is working with the UK Department of Health and existing support schemes with the aim of delivering increased

financial support through some of the existing schemes during the 2016-17 financial year. A further announcement on the timescales for implementation will be made in due course.

Scottish Infected Blood Forum SIBF welcomes Scottish Government decision on Contaminated Blood but argues more needs to be done. 18 March 2016

The Scottish Infected Blood Forum¹ welcomes the Scottish Government's announcement that it has accepted the key recommendations proposed by the Financial Review Group² Final Report³.

The proposals are a step forward in providing some form of justice for the innocent victims of the "worst treatment disaster in the history of the NHS"⁴.

In particular SIBF acknowledges the Cabinet Secretary Shona Robison's support, the careful way she listened to victims and the continuing efforts she has made to produce this part of the settlement.

However, the Forum remains critical of the failure to address the issues of the majority of victims who do not qualify for annual payments (so-called 'stage 1'⁵) due to inappropriate and outmoded arbitrary illness thresholds, as detailed in SIBF's Note of Dissent⁶. According to the work of the Penrose Inquiry, stage 1 victims account for approximately 80% of all those infected.

For those infected in Scotland, the Scottish Government has committed to:

- Increase annual payments for those with advanced Hepatitis C (at Stage 2⁵), HIV and for those co-infected with both Hepatitis C and HIV.
- Provide annual payments to widows and widowers of those who have died as a result of their advanced (Stage 2) Hepatitis C or HIV infection.
- Provide a lump sum of £30,000 to all those who are infected with chronic Hepatitis C at Stage 1. This will mean that victims in Scotland will finally receive the amount of money that Lord Ross's Expert Group recommended in 2003, some 13 years ago.
- Increase Scottish Government funding for a Support and Assistance grants scheme for those infected and their families to £1 million per year.

As detailed in SIBF's Scoping Exercise⁸, many victims who are classified as stage 1 (the 80%) are chronically ill as a result of receiving contaminated blood and blood products from the NHS, and the side-effects of past treatments, and have been forced out of employment due to health issues caused by the infection. Many have suffered, and continue to suffer, substantial financial hardship due to being State infected. They, their families and the families of those who have died

should be treated with equal primacy together with those who have been classed Stage 2.

SIBF Convener, Philip Dolan MBE commented "We welcome the Scottish Government's statement which is a step forward in obtaining some justice for victims. SIBF and partner organisations will continue to lobby and argue for a full, fair and equal settlement for the needs of the majority, who seek to live out the remainder of their lives with financial stability and dignity". He added "There is no guarantee that the ongoing needs of the majority who are deemed to fall below Stage 2 will be met. The fear is that more people from this key group will die before a satisfactory and just financial settlement is provided to them".

SIBF's position is detailed in the Note of Dissent Position Paper⁶ which was included in the Group's Final Report.

The Forum welcomes the opportunity to continue the work with the Scottish Government and others, when the Financial Review Group reconvenes after the Scottish Parliament elections, to ensure that this part of the settlement is paid promptly to victims. SIBF hopes that the Department of Health in London will offer every assistance in a timely fashion to support the direction of travel in Scotland.

For further information, please contact: Philip Dolan MBE, Convener of the Scottish Infected Blood Forum tel: 07974 823937 / 0141 649 0050, email: pdolan614@btinternet.com

Notes to Editors:

- 1. Established in 2012, the Scottish Infected Blood Forum is the only recognised charity in Scotland that seeks to provide support for those who have been infected or affected with hepatitis C as the result of NHS contaminated blood, including those with haemophilia and those who received blood transfusions. It also provides a voice for those who have been unable to give oral evidence to the widely criticised Penrose Inquiry. The precursor organisation to SIBF, the Scottish Haemophilia Forum, had been lobbying the Scottish Government since 1999 when the Scottish Parliament was reconvened.
- 2. The Financial Review Group was convened after the Penrose Inquiry Final report was published in March 2015 and was chaired by Ian Welsh OBE, Chair of the ALLIANCE (Health and Social Care Alliance Scotland). It involved a range of affected groups, both infected individuals and family members, together with Scottish Government civil servants and lawyers. They provided their recommendations to Ministers in December 2015.
- 3. The Financial Review Group Final Report, published by Haemophilia Scotland, can be downloaded from www.sibf.org.uk
- 4. Described by professor, medical doctor and broadcaster, Lord Robert Winston, Lords Hansard text for 22 Oct 2010 (pt 0001)
- 5. Victims have been categorised in 'stages', based on the criteria established by The Skipton Fund. Stage 1 victims are those who have contracted Hepatitis C from contaminated blood and blood products, or have acquired it from someone who was infected.

- Stage 2 victims are those who have went on to develop advanced liver disease as a result of the infection.
- 6. The SIBF Note of Dissent can be viewed in full at www.sibf.org.uk
- 7. The Hepatitis C Skipton Fund was set up in 2004 to help those who were infected with the disease through treatment on the NHS, or through contact with someone who had such treatment. There are three stages of payment, depending on the stage that the infection has reached in the person claiming on the fund.
 - i. The first stage is a payment of £20,000, which is paid out to those who have Hepatitis C that has not cleared spontaneously.
 - ii. A further £50,000 is paid out to those who have the most serious effects of the Hepatitis C virus, such as cirrhosis of the liver.
 - iii. A further annual payment is then paid out to those who have advanced liver disease (as set out in the scheme) or B-cell non-Hodgkin's lymphoma.
- 8. The SIBF Scoping Exercise Final Report can be downloaded from www.sibf.org.uk and contains responses and comments from over 120 people infected or affected as a result of receiving contaminated blood.

Haemophilia Society Initial response to the contaminated blood consultation 22 January 2016

Following the long awaited launch of the government consultation 'Infected blood: reform of financial and other support', The Haemophilia Society is shocked and angry that the proposals suggest that the majority of people in our community who have been impacted by this terrible situation will be financially worse off in the new scheme, and will receive significantly lower income than their peers in Scotland, if the current proposal is accepted there. The Government's headline may be more resources, but the truth appears to be rather different. Many of the most disadvantaged people will lose out. We will be undertaking a full analysis, seeking legal advice and supporting our members to understand the implications of this proposal, enabling us to respond to the consultation with strong evidence.

It is important to stress these proposals are only a consultation and it is vital that the community's voice is heard. We will be briefing parliamentarians on the impact these proposals will have and will also be publishing materials to help our members have their say. We will be taking action at Westminster to ensure that our concerns our heard loud and clear. We hope that ministers will listen.

Statement from the All Party Parliamentary Group on Haemophilia and Contaminated Blood in response to the publication of the Penrose Inquiry March 2015

The Contaminated Blood Scandal was the biggest disaster in NHS history. It was right that there was a judicial inquiry. We wish to express our appreciation for the commitment Lord Penrose has given, and hope he recovers from his illness. Given that the report extends to 5 volumes and over 1800 pages it will take some time to digest, but we share the surprise of many of those affected that the Inquiry only made one recommendation.

Today we should remember all those who contracted HIV and Hepatitis C and their families; for them this is not a historic issue but an ongoing tragedy which continues to have a devastating impact on their lives. Lord Penrose was right to say this was the stuff of nightmares.

The apology from the Prime Minister on behalf of the UK Government is a significant moment in a long struggle for recognition of the scale of this tragedy, and we welcome this. What we need now is a proper system for supporting and compensating all those affected. The APPG Inquiry last year showed that the current support system is simply not meeting the needs of those it is meant to help and is not fit for purpose.

There were some positive steps today: we welcome the announcement of £25m for transitional funding and we welcome the commitment from both party leaders that whoever forms the next Government they will provide a permanent settlement for all those affected. This is not the end of the matter further steps need to be taken in keeping with MPs previous recommendations.

We will continue to support those affected, and those who have been left behind. After decades of injustice a lasting settlement is long overdue.

4. Parliamentary material

4.1 Parliamentary Questions

Blood: Contamination

Asked by: Kinnock, Stephen

To ask the Secretary of State for Health, pursuant to the Answer of 17 December 2015 to Question 19788, in how many cases liability has been established for people infected by contaminated blood.

Answering member: Jane Ellison | Department: Department of Health

In 2001 the National Blood Authority was liable for the infection of 117 patients with hepatitis C between March 1988 and September 1991 by whole blood transfusion. The litigation was brought under the provisions of the Consumer Protection Act 1987. The litigants were awarded quantum based damages.

HC Deb 22 January 2016 | PQ 22461

Blood: Contamination

Asked by: Ritchie, Ms Margaret

To ask the Secretary of State for Health, when compensation will be made available for those individuals infected by contaminated bloods.

Answering member: Jane Ellison | Department: Department of Health

As liability has not been established in the majority of cases, therefore it would not be appropriate to talk about payments in terms of compensation. Where liability has been established in a small number of individuals affected by HIV, hepatitis C or both infections through treatment with NHS-supplied blood or blood products before 1991, compensation has been paid. A consultation on proposals to reform the current payments schemes will be published in January 2016.

HC Deb 17 December 2015 | PQ19788

Blood: Contamination

Asked by: Kwarteng, Kwasi

To ask the Secretary of State for Health, what progress has been made on securing funding for patients infected with contaminated blood and for their families.

Answering member: Jane Ellison | Department: Department of Health

The Department is considering wider reform of financial assistance and other support for those affected with HIV and/or hepatitis C by infected NHS-supplied blood or blood products. We are doing this within the context of the spending review and in a way that is sustainable for the future. We plan to consult on a way forward before the end of the year. Before the election, the Prime Minister announced an additional one-off £25 million to ease transition to a reformed system of payments for affected individuals. The Department is currently considering how that money will be used.

HC Deb 21 Oct 2015 | PQ 11638

Blood: Contamination

Asked by: Monaghan, Dr Paul

To ask the Secretary of State for Health, what arrangements have been made to distribute the £25 million of additional compensation to people infected with contaminated blood; when he plans to report progress on this matter to the House; and if he will make a statement.

Answering member: Jane Ellison | Department: Department of Health

On 25 March, the Prime Minister announced that £25 million would be allocated to support transition to a reformed scheme. A written ministerial statement (HCWS146) was given on 20 July, stating that no decision has yet been made but it will be used appropriately to support any transitional arrangements once we have consulted on how a new scheme might be structured.

HC Deb 23 July 2015 | PQ 7788

Asked by: Rory Stewart (

One of the most disturbing scandals has been the infection of thousands of people across the nation with HIV and hepatitis C through contaminated blood. Today Lord Penrose publishes a report that follows nearly 25 years of campaigning by Members on both sides of this House to address the scandal. Will the Prime Minister, as the last act of his Government, ensure that there is a full apology, transparent publication and, above all, proper compensation for the families terribly affected by this scandal?

Answering Member: The Prime Minister:

My hon. Friend is absolutely right to raise this, with the Penrose report being published today. I can do all of the three things he asks for. I know that many Members on all sides of this House have raised the question of infected blood, and I have spoken about how constituents have been to my surgeries. While it will be for the next Government to take account of these findings, it is right that we use this moment to recognise the pain and the suffering experienced by people as a result of this tragedy. It is difficult to imagine the feelings of unfairness that people must feel at being infected with something like hepatitis C or HIV as a result of a totally unrelated treatment within the NHS. To each and every one of those people, I would like to say sorry on behalf of the Government for something that should not have happened. No amount of money can ever fully make up for what did happen, but it is vital that we move as soon as possible to improve the way that payments are made to those infected by this blood. I can confirm today that the Government will provide up to £25 million in 2015-16 to support any transitional arrangements to a better payments system. I commit that, if I am Prime Minister in May, we will respond to the findings of this report as a matter of priority. Finally, I know that Lord Penrose was unable to present the findings of his report today because of illness. I am sure the whole House would

want to send him our very best wishes. HC Deb 25 March 2015 | Vol 594 c 1422

Blood: Contamination

Asked by: Mr Tom Clarke

To ask the Secretary of State for Health (a) how many and (b) what proportion of people infected by contaminated blood through NHS blood transfusions have since died.

Answering member: Jane Ellison | Department: Health

Approximately 100 people were infected with human immunodeficiency virus (HIV) in the United Kingdom as a result of treatment with NHS blood transfusions, before a screening test for donated blood became available in 1985. As at 30 September 2013, 17 are known to be alive and registered with MFET Ltd, which makes payments in respect of infection with HIV, which implies that around 83% have died. Approximately, a further 1,200 people were infected with HIV as a result of treatment for inherited bleeding disorders, primarily haemophilia, with plasma-derived clotting factor products, before safer products became available in 1985. As at 30 September 2013, 353 are known to be alive and registered with MFET Ltd, which implies that around 71% have died.

In relation to hepatitis C, the Government's 2010 'Review of the Support Available to Individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants' estimated that approximately 28,000 individuals were infected in the UK as a result of NHS blood transfusions before a screening test for donated blood became available in 1991. A copy of the report has already been placed in the Library. As at 30 September 2013, 2,442 of those individuals had received at least one payment from the Skipton Fund Ltd in respect of chronic infection with hepatitis C. Of these individuals, the Skipton Fund has been notified of 320 deaths, which represents approximately 13% of the total number of individuals who have received at least one payment.

The UK Haemophilia Centres Doctors' Organisation estimated in 2011 that a further 4,689 people with inherited bleeding disorders were exposed to hepatitis C through treatment with NHS supplied plasmaderived clotting factor products, before safer products became available in 1985. As at 30 September 2013, 2,648 of those individuals had received at least one payment from the Skipton Fund Ltd in respect of chronic infection with hepatitis C. Of these individuals, the Skipton Fund has been notified of 665 deaths, which represents approximately 25% of the total number of individuals who have received at least one

However, the Skipton Fund does not routinely receive death notifications in respect of those who do not receive annual payments. There is no other information on those who may be infected by hepatitis C as a result of NHS-supplied blood or blood products held centrally, from which the Department can make a more accurate estimate.

HC Deb 24 October 2013 | PQ 171861 | Vol 569 c248W

4.2 Parliamentary **Proceedings**

Statement: Infected Blood

HC Deb 21 January 2016 | Vol 604 cc1582-1592

The Parliamentary Under-Secretary of State for Health (Jane

Ellison): In the urgent question on 16 December, I committed to publishing the consultation on infected blood scheme reform in January. I am pleased, therefore, to announce the launch of that consultation. I recognise that for some this will come too late. I cannot right the pain and distress of 30 years, and the truth is that no amount of money could ever make up for the impact that this tragedy has had on people's lives. As I have said before, for legal reasons, in the majority of cases, it is not appropriate to talk about compensation payments, but I would like to echo what has been said before in the House and say sorry on behalf of the Government to every person affected by this tragedy. Scheme reform is a priority for me and the Government, and for that reason I can announce that the Department of Health has identified £100 million from its budget for the proposals in the consultation. This is in addition to the current spend and the £25 million announced in March 2015, and it will more than double our annual spend on the scheme over the next five years. This is significantly more than any previous Government have been able to provide for those affected by this tragedy.

I know all too well of the ill health and other impacts on many of those affected by the tragedy of infected blood. I have corresponded with many of those affected and their MPs—they each have their own story to tell—and I have reflected carefully on all this in developing the principles on which the consultation will be based. These are: that we focus on those infected; that we can respond to new advances in medicine; that we provide choice where possible; and that we maintain annual payments to everyone currently receiving them. The consultation is an opportunity for all those affected to have their say, and it is important that it extends to the guieter voices from whom we hear less often.

It is not appropriate, and I do not have time, to go through the whole consultation document today, but I would like to highlight some of its key components. A large population within the infected blood community currently does not receive any regular financial support. These are the people with hepatitis C. I believe it is important that everybody receives support from the new scheme and that it be linked to the impact infection has on their health. I therefore propose that all those registered with the schemes with hepatitis C at current stage 1 be offered an individual health-based assessment, completion of which would determine the level of annual payment received. This would also apply to anyone who newly joins the scheme.

The consultation document outlines our proposal that those currently receiving annual support should have their payments uplifted to £15,000 a year. Those who are co-infected and currently receive double payments would continue to do so. I often hear that people are unhappy about applying for discretionary charitable payments. I hope

that the introduction of new regular annual payments will remove this requirement. I am keen that those who respond to the consultation take the opportunity to answer all the questions about the support proposed so that I can make informed final decisions on the shape of any new scheme once all the responses have been collected and analysed. During the urgent guestion, I said I was interested in the opportunities offered by the advent of simpler and more effective treatments that can cure some people of hepatitis C. The NHS is at the start of its programme to roll out the new hepatitis C treatments previously approved by the National Institute for Health and Care Excellence. As Members will know, the NHS must prioritise treatment on clinical need and not on route of infection, which means that, although some in the infected blood community will be eligible for treatment right away, others might have to wait.

More than anything, I want, if we can, to give the chance to limit the impact of hepatitis C on the infected community by making an offer of treatment. Over recent months, I have received many letters from people expressing a wish to halt the progress of their infection—one of the many letters that particularly struck me asked simply: "Please make me well"—so my intention is that the new scheme will provide an opportunity to enhance access to treatment, especially for those who fall just short of the current NHS criteria. I hope that we can treat more people if finances allow. That is why the consultation is seeking views on offering treatment to those with hepatitis C in the infected blood community not yet receiving treatment on the NHS.

In keeping with the principle of offering choice where possible, I am pleased to announce that we are consulting on a choice of options for the bereaved. Currently, bereaved partners or spouses are eligible to apply for means-tested support from the charities. As I have said, I have heard concerns from many people who do not like having to apply for charity. With that in mind, the consultation offers the choice of continued access to discretionary support or a one-off lump-sum payment for the bereaved based on a multiple of their current discretionary support. There are questions on this in the consultation document, and I am keen to hear from those affected so that I can understand their preference.

Having listened to concerns about the complex nature of the five schemes, the consultation proposes that, following reform, there will be one scheme run by a single body with access to expert advice, including from National Institute for Health and Care Excellence, so that we can keep pace with any new advances in treatment for hepatitis C and HIV that emerge.

On the next steps, the consultation will be published today on gov.uk and will run until 15 April. This is a 12-week consultation to ensure that all those who wish to respond have time to do so. The consultation document contains guestions about the proposals on which I would welcome views. I recognise that there has been disappointment that we have not consulted sooner, but the outcome of the consultation will be crucial to informing our final decisions about how to proceed, and I give the House, and those affected, my commitment that we will proceed as rapidly as possible to implementation thereafter.

We need, as a priority, to make progress in rolling out the health assessments as guickly as possible to ensure that people get access to the support and clinical advice they need. I should be clear, however, that my intention is that annual payments for the current stage 1 cohort should be backdated to April 2016, regardless of when each individual's assessment takes place.

This is the first time that the Government are consulting fully and widely with the entire affected community and all those who might have an interest on the future reform of the scheme. In developing the proposals to include within the consultation, I have taken account of points I have heard in debates here, of correspondence sent to me, of my discussions with the all-party group and of views gathered during pre-consultation engagement. The consultation is now open and it is my hope that all those affected by this tragedy will respond, and that we can move forward from here. I commend the statement to the House. http://www.publications.parliament.uk/pa/cm201516/cmhansrd/cm160 121/debtext/160121-0002.htm#16012124000004

Victims of Contaminated Blood: Support

Urgent question on Government plans to reform the support for victims of contaminated blood.

HC Deb 16 December 2015 | Vol 603 cc1533-1565

http://www.publications.parliament.uk/pa/cm201516/cmhansrd/cm151 216/debtext/151216-0001.htm#15121621000002

Westminster Hall debate: Contaminated Blood Products HC Deb 09 September 2015 | Vol 599 cc79-88WH http://www.publications.parliament.uk/pa/cm201516/cmhansrd/cm150

909/halltext/150909h0001.htm#15090925000002

Contaminated Blood

Urgent guestion on the support available to victims of contaminated blood.

HC Deb 20 July 2015 | Vol 598 cc1221-1232

http://www.publications.parliament.uk/pa/cm201516/cmhansrd/cm150 720/debtext/150720-0001.htm#1507202000004

Penrose Inquiry

Urgent question on the publication of the Penrose inquiry and its implications for the United Kingdom Government. HC Deb 26 March 2015 | Vol 594 cc1592-9

http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150 326/debtext/150326-0001.htm#15032622000002

Written Statement: Infected blood HC Deb 25 March 2015 | HCWS480 Mr Jeremy Hunt (The Secretary of State for Health): In January 2011, my predecessor, the Rt. hon. Member for South Cambridgeshire (Andrew Lansley) recalled with sadness how what happened during the 1970s and 1980s, when thousands of patients contracted hepatitis C and HIV from NHS blood and blood products, is one of the great tragedies of modern health care. I would like to say on behalf of this Government how sorry we are for what happened, and express my sympathy for the pain and grief suffered by many infected people and their families.

Since 1988, the Government has established a number of schemes to provide financial support to people affected by that tragedy. The system has evolved in an ad hoc and incremental manner, now comprising five infection focussed schemes that operate according to their own individual criteria. In January 2011, this Government acknowledged the system then had shortcomings and introduced a number of improvements. Despite these improvements, there have been continued criticisms of the system, as reflected in the reports produced earlier this year by the hon. Member for North East Bedfordshire (Alistair Burt), and by the All Party Parliamentary Group (APPG) for Haemophilia and Contaminated Blood, and described by honourable friends and members across the House during the Back Bench Business Committee debate held on 15 January 2015.

From listening to a range of views on the current system, it is apparent that there might be some people who are experiencing significant ill health which may result from their infection(s) who feel they are not well supported by the existing system. However, it is important to recognise there are elements of the current system which do find favour among the beneficiary community. The challenge for any future Government will be to identify the most appropriate way of targeting financial assistance, whilst ensuring that any system can be responsive to medical advances and is sustainable for Government in financial terms.

I thank both the hon. Member for North East Bedfordshire (Alistair Burt) and the APPG for their reports, both of which we are considering carefully. It is with frustration and sincere regret that our considerations on the design of a future system have been subject to postponement whilst we awaited publication of Lord Penrose's final report of his Inquiry in Scotland. We had hoped to consult during this Parliament on reforming the ex-gratia financial assistance schemes, considering, amongst other options, a system based on some form of individual assessment. However, I felt that it was important to consider fully Lord Penrose's report before any such consultation. Given its publication today, we clearly are not in a position to launch a consultation, on one of the last sitting days of this Parliament.

However, Lord Penrose's report has now been published. It can be found on the Inquiry website at: http://www.penroseinquiry.org.uk/. Whilst it will be for the next Government to consider all of Lord Penrose's findings, I would hope and fully expect proposals for improving the current complex payment system to be brought forward, with other UK Health Departments.

In the meantime I am pleased to announce that I will be allocating up to an additional one-off £25 million from the Department of Health's 2015/16 budget allocation to support any transitional arrangements to a different payment system that might be necessary in responding fully to Lord Penrose's recommendations. We intend this to provide assurances to those affected by these tragic events that we have heard their concerns and are making provision to reform the system.

Finally I can formally announce that, in line with our consistent policy of openness, we are now preparing for transfer to the National Archive remaining Department of Health documents relating to blood safety for the period from 1986 to 1995. These documents, which will be open for public scrutiny, will be followed by subsequent tranches of documents covering later years.

Whilst I recognise that this statement does not immediately fulfil the desires of all who campaign on this matter, I hope that it signposts this Government's positive direction on these matters.

Backbench Debate: Contaminated Blood HC Deb 15 January 2015 | Vol 590 cc1025-1075 http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150

115/debtext/150115-0001.htm#15011554000001

5. Useful links and further reading

Department of Health open consultation *Infected blood: reform of* financial and other support closes 15 April 2016 https://hopuk.sharepoint.com/sites/DIS/Research/SitePages/Guidance.asp Χ

The All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood *Inquiry into the current support for those affected* by the contaminated blood scandal in the UK January 2015 http://www.haemophilia.org.uk/what we do/influencing advocacy/app a hcb fr.pdf

Penrose Inquiry

This is the website for the Scottish Public Inquiry into Hepatitis C/HIV acquired infection from NHS treatment in Scotland with blood and blood products. It was set up by Scottish Ministers under the Inquiries Act 2005. It was announced by Nicola Sturgeon MSP, the Cabinet Secretary for Health and Wellbeing on 23 April 2008. The Rt Hon Lord Penrose is the Chairman of the Inquiry http://www.penroseinguiry.org.uk/

Final report 25 March 2015 http://www.penroseinguirv.org.uk/finalreport/

Contaminated Blood: Financial Support: Conclusions and Recommendations Financial Review Group Final Report March 2016 la review of the existing UK-wide financial support schemes for individuals infected with hepatitis C and HIV through NHS blood and blood products, in respect of individuals infected in Scotland and their families/carers1

http://sibf.ninedesignstudio.co.uk/contaminated-blood-financialsupport-conclusions-and-recommendations.pdf

Review of the support available to individuals infected with Hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants updated March 2011

https://www.gov.uk/government/uploads/system/uploads/attachment_d ata/file/215828/dh 125977.pdf

Contaminated Blood Campaign http://contaminatedbloodcampaign.co.uk/

taintedblood.info exists solely to support and to achieve justice for those infected and affected by contaminated blood and blood products in the United Kingdom.

http://www.taintedblood.info/index.php

Haemophilia Society http://www.haemophilia.org.uk/

Scottish Infected Blood Forum http://sibf.ninedesignstudio.co.uk/

The Hepatitis C Trust http://www.hepctrust.org.uk/

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