

The Haemophilia Society proposal to Government: Establishing a new system of support for those impacted by the Contaminated Blood tragedy

Overview

The Haemophilia Society believes that following Prime Minister David Cameron's commitment at the end of the last Parliament it is now urgent to bring about a swift and fair resolution to the contaminated blood campaign. This document has been informed by our members' experiences, our involvement with the APPG on Haemophilia and Contaminated blood, and the work of Alistair Burt MP, together with the evidence of the Archer and Penrose Inquiries.

We propose a decision-making process which we believe will be seen to be measured and fair both by those affected and by Government. Its goals are to define a level of support which will fairly recognise how different groups of people have been impacted, to specify a means of distribution which will be respectful to the beneficiaries, and to put in place processes to ensure that the system proves robust over several decades as the population of those impacted ages. As this will undoubtedly require greater funding than the current system, it needs to be properly costed and accepted by the Government as a long-term commitment. The Government will require evidence of due process in the design of such a system, and the affected community will need to feel involved in the process for the outcome to be successful. The process therefore needs to be industrial strength and to rely on independent experts covering the full range of capabilities required.

The output should be

- identification of needs for those impacted
- specification of a fair level of support for each subgroup identified
- design of a distribution mechanism for support which will be effective and independent of government
- a credible financial projection of the costs involved so that the Government can approve a long-term commitment to the expenditure
- A mechanism for maintaining independent review over the implementation of the agreed scheme.

In addition, to be politically acceptable the process must make every effort to produce an outcome which is seen as fair by those impacted by contaminated blood. Accordingly, it should involve representatives of those affected and must give them the chance to review, speak, and vote at every stage of decision making. While those impacted cannot have a veto on decisions, they should be ensured a strong influence.

A key requirement is that the process is completed as soon as is practical; we recommend a timescale of achieving Government approval for a new system within six to eight months of agreement on the Terms of Reference.

It should be recognised that these requirements mean that the process will involve some 20 people over a period of several months, while this is complex and undoubtedly unsatisfactory to those who have already waited so long, it is nevertheless appropriate for setting up a structure intended to support more than 3,000 individuals and families over decades, and which will involve significant government expenditure.

The process proposed here can undoubtedly be improved, but any viable alternative would be likely to be of a similar scale. We believe that it is better to adopt a process which is 90% correct quickly than to spend months arguing about small improvements.

The Haemophilia Society does not have the remit to comment on support for people who do not have a bleeding disorder and who have been infected through whole blood products. We are sympathetic to there being a parallel process to establish a system of support for them, but we believe that it would be counterproductive to try to reach a settlement for both groups through a single process.

Proposed structure and process

The Haemophilia Society proposed structure requires:

- Terms of Reference defining goals and an organisational structure
- Identification of roles to fill in the organisational structure including independent experts covering all necessary areas
- Definition of a process including a timetable

Overall Terms of Reference

- Create a working group visibly independent of Government, incorporating experts in appropriate fields, together with representatives of those impacted by contaminated blood. The members of the working group will be appointed by different independent bodies as documented below under “organisation”. The Government will have the right to request alternatives to those appointed on reasonable grounds such as they are not adequately qualified or have conflicts of interest.
- Through a liaison group (chosen as explained under “organisation below) meet regularly with representatives of Government in order to maximise communication and to understand what the Government’s position is likely to be on important issues.
- Early in the process establish
 - A plan to deliver recommendations within 6 months from the first meeting of the Plenary Committee
 - An overall definition of level of support to aim at (this is expected to enable people to live financially independent lives without the need for benefit support, and to have security in housing and stability for their family after death). This definition should be discussed with the Government’s representative as soon as possible to establish whether the Government is likely to agree
 - An overall definition of the health and social care support to be delivered to the affected community
- Establish need
 - Different categories of those impacted (including those currently excluded from support by the trusts)
 - Definition of need overall and for each category, taking into account historic needs not recognised or not fully recognised in all cases, such as those with a diagnosis of hepatitis C pre-cirrhosis and widows/life partners and children of people infected with hepatitis C.

In establishing need, consideration should be given to arrangements reached in other countries and in comparable situations such as the Thalidomide tragedy.
- Design a distribution mechanism including
 - Organisational structure

- Mechanism for ensuring independence from Government
 - Process for transfer of people from existing trusts
 - Process for taking on board new people
 - Process for “look back” to identify people previously submitted to the trusts but rejected or timed out
 - Process for independent appeal against decisions on support, taking into account best practice from parallel situations.
- Estimate the cost per year of additional support with an actuarial projection of costs over time
 - Obtain and take into account comments of a representative group of those impacted by contaminated blood in all decision making. This should include representatives from the existing campaign groups, The Haemophilia Society and those who have not been involved in campaigning, but are affected.
 - Specify a mechanism for independent review of the implementation of the agreed scheme
 - Deliver recommendations to the Government within 6 to 8 months of agreement to these Terms of Reference.

Organisational structure

This will comprise a Plenary Committee comprising all persons in the working group. There will be specialist subcommittees, being:

- Steering
- Needs
- Distribution
- Impacted
- Finance

Membership of these is as defined in Table 1.

The Government should provide a secretariat to the process and secretarial support to the Chair, and will pay all expenses for the process including normal travel and sustenance expenses to members. In recognition of the difficult history of this subject, it would be appreciated by the affected community if meetings could take place in offices other than in the Department of Health.

Table 1

Members of Plenary Committee (22 people)	Membership of subcommittees				
	Steering	Needs	Distribute	Impacted	Finance
Chair – QC, with relevant experience, such as medical compensation or a Human Rights expert.	YES				
Department of Health representative	YES	YES			
Department of Works and Pensions representative to be expert in distribution of benefits	YES		YES		
Advisor to the Impacted subcommittee – senior solicitor experienced in medical compensation to be appointed by the Law Society				YES	
3 representatives from the main Campaign Groups (ie. 1 from each group)	YES 1	YES 1	YES 1	YES 3	
5 times other impacted people with broad representation across the UK and impacted groups to be appointed by The Haemophilia Society	YES 1	YES 1	YES 1	YES 5	
CEO of The Haemophilia Society	YES				
Haemophilia doctor who was not practicing at the time infections occurred, to be appointed by UKHCDO	YES	YES			
A Gerontologist to be appointed by The Royal College of Physicians		YES			YES
Virologist or appropriate physician or academic expert in projecting morbidity and mortality in those impacted	YES	YES			YES
Expert in evaluating medical needs for benefits/compensation		YES	YES		
Expert in running schemes for distributing medical benefits eg Charity CEO or Operation Director	YES		YES		
Health economist expert in evaluating long-term cost of care for individuals and groups			YES		YES
Actuary to be appointed by the Institute of Actuaries	YES				YES
Accountant to be appointed by the Institute of Chartered Accountants (or other accountancy institute)					YES
Total	10	7	6	9	5

Up to 3 additional slots for Plenary for additional experts to be appointed as the need is identified.

The independent Chair should be appointed by the Minister in conjunction with the Bar Council and with the approval of a group comprising

- A representative of the DH
- A member of The APPG on Haemophilia and Contaminated Blood
- The Haemophilia Society CEO
- Two affected people to be recommended by The Haemophilia Society.

The Chair will then lead the appointment of the Plenary positions, except for the affected people where the Haemophilia Society will lead.

Outline terms of reference of Plenary Committee and Subcommittees

Plenary

- Will agree all output of the process and timetable
- Will aim for consensus, but if none can be achieved will go with majority, with the Chair having a casting vote
- If the affected community members vote as a body (with maximum 1 voting against or abstaining) against a majority vote, this (along with a short comment agreed by those affected who are voting) will be noted in the minutes and on all documents published by the Plenary Committee with the request that all recipients of the minutes or such documents shall record the dissent of those impacted in any redacted document
- At the earliest opportunity will receive a recommendation from the Steering Committee on the definition of “overall level of support”; this will include financial, health, and social care elements. Plenary will vote on this and will contact the responsible Minister through the liaison group to get the Government’s agreement within a defined timescale
- May co-opt additional independent experts as required at the request of the appropriate subcommittee or may co-opt up to one additional independent expert on its own decision

Steering

- To be chaired by the Chair of the Plenary Committee
- Will meet more regularly than the Plenary Committee to organise the workload and drive the process.
- At the earliest opportunity will consult with the Needs and Impacted subcommittees and others to recommend a definition of “overall level of support” and will place this for decision with the Steering Committee
- Shall co-opt replacements for representatives resigning or otherwise unable to continue, using the same selection process as was used in the original selection for that role.

Needs

- Will produce a report defining
 - Different groupings of those impacted (including those currently excluded from trusts)
 - Definition of need, overall and for each grouping
 - Take into account historic needs not given adequate support previously such as: those with a diagnosis of hepatitis C pre-cirrhosis, widows/life partners and children of people infected with hepatitis C, and those identified as at risk of vCJD
 - Identify health and social care requirements including recommendations for any appropriate early access to the best possible physical and mental health care, social services and any other health or social care requirements identified

In all of the above, the subcommittee will take into account arrangements reached in other countries and in parallel situations.

Distribution

- Design a distribution mechanism
 - Organisational structure
 - Process for transfer of cases from existing trusts
 - Process for taking on board new people

In all the above, the subcommittee will take into account best practice from arrangements reached in other countries and in parallel situations.

Finance

- Given output from Needs subcommittee, to evaluate cost per year using actuarial projections
- Given output from the Distribution subcommittee to evaluate cost per year of proposed mechanism.
- To evaluate cost of current support, including direct costs and hidden costs through the benefits system and through additional costs to the NHS
- To provide constructive challenge to output supplied by Needs and Distribution subcommittees
- To support subcommittees and Plenary Committee as required

Each of the Needs, Distribution, and Finance subcommittees may co-opt up to three additional experts to attend if they identify these as needed, but these shall become voting members and members of Plenary only if approved by Plenary.

Impacted

- To make its best efforts to represent the views of all those impacted by contaminated blood, recognising the need to balance competing claims and to achieve a fair distribution of resources available
- To review proposals from Needs, Distribution, and Finance and to provide constructive criticism
- To comment in particular on proposals which the subcommittee believes will be considered totally inequitable by those impacted
- To have all their output circulated as papers for the Steering subcommittee and Plenary committee and other subcommittees as appropriate

Liaison group

- To comprise the Chair of Plenary, one person appointed by the Steering committee, and one person appointed by the Impacted subcommittee
- To report to the Steering committee and as required to Plenary.
- To meet regularly with representatives of Government to maximise communication and to obtain timely understanding of the Government position in principle on emerging issues

Process

The Plenary will meet as soon as possible. As part of its first meeting, there will be short breakout meetings of the Needs, Distribution, Finance, and Impacted subcommittees, which will each elect a chair and agree a timetable for their meetings to be at least one a month. In addition the Impacted subcommittee will elect its representatives to the Steering committee and to the other subcommittees. The Steering Committee will then hold a short breakout meeting and agree a timetable for its meetings, to be at least eight times in a projected six month period.

At its first full meeting, the Steering committee will draft (1) a project plan and (2) an “overall level of support”. These will be discussed and approved with any amendments by the immediately following Plenary.

The Haemophilia Society recognise this will be a complex and challenging process, which will face difficult negotiations and hard choices in order to deliver a viable scheme in a short time. However we believe this structure and broad representation is the only way to ensure resolution in a reasonable timescale for those who have been waiting far too long for reasonable financial independence, health, and social care, following the tragedy of contaminated blood.

The Haemophilia Society call on the Government to respond constructively and in detail to this proposal within four weeks.