Summary:

The purpose of this document is to recommend to Government the measures we feel they should take in order to bring about closure to the majority of haemophiliacs infected and affected by contaminated blood products.

This has involved the gauging of opinion of those affected via a variety of means and has involved a large proportion of those affected. We believe that the recommendations below accurately reflect the views of the majority of the wider community and that this is fundamental to achieving closure.

Lord Archer’s recommendations have become the widely accepted model that haemophiliacs in the UK believe to be an appropriate way of resolving this issue once and for all. We acknowledge and support the Prime Minister’s comments that the previous Government was wrong in its failure to engage meaningfully with Lord Archer’s inquiry.

Key Recommendations:

1. To implement a compensation scheme whereby applicants have a choice in how they receive the payments, with all awards calculated via individual assessments.
2. To be fully inclusive of all those infected and affected, with no arbitrary cut off dates or exclusions.
3. To provide free NHS care for all health needs, and to establish a comprehensive insurance scheme.
4. To extend patient representation in health care decision making and to establish a Royal Commission to investigate the facts behind this tragedy. The Royal Commission should also review the Medicines Act to ensure that it incorporates advances made in organically derived treatments.

In addition to these recommendations, we strongly request Government support for a full debate on this tragedy in the House of Commons. We put our faith in our democracy and our Parliament and welcome the opportunity to have our case heard in a democratic debate, thereby submitting ourselves to the will of Parliament.
The Recommendations:

1. **What kind of financial relief would best bring closure?**

   The majority of those questioned would like a one-off lump sum. However, there was a significant number who wished for an option including a lump sum followed by ongoing payments.

   **Recommendation:** We believe that all of these choices could be accommodated by Government by giving people the choice of how they would like their payment awarded. This would have the added benefit that in approximately half of cases Government would not have to find the whole amount payable at once. We also believe that there could be further room for negotiation on how lump sums are paid. If the applicant takes any on-going payment, this payment should rise in line with the RPI. It is essential that there are no arbitrary cut-off dates, as has happened in the past to widows wishing to access Skipton Fund payments.

2. **Should there be an interim lump sum awarded?**

   As part of the above question, respondents were asked if they wanted an initial interim lump sum to be awarded while the scheme is being finalised.

   **Recommendation:** That an interim lump sum be paid immediately to those infected or affected irrespective of multiple infections, severity of impact etc. (One payment per infectee, payable to the infectee or his/her estate). We believe this initial measure would show a true willingness by Government to deal with this issue and would allow the necessary processes to be finalised to calculate and pay the balance of any compensation.

3. **How Should Awards be evaluated?**

   There was no conclusive indication of which method would be preferred between individual assessment, table of payments or a flat rate payment to everyone. Individual assessment was the method chosen in Ireland, which was the model for Lord Archer’s recommendations and has been fundamental to achieving closure there. We would therefore strongly recommend that the Government should adopt this method of evaluation. Individual assessments would also avoid the comparisons between how different groups of infectees are compensated, as any awards would be confidential between claimant and panel.

   **Recommendation:** That an individual assessment is made of the impact of the viruses on each claimant.

4. **Who should sit on the assessment panel?**

   An overwhelming majority of people would like to see a special panel of assessors that consists of a mixture of people including compensation/damage assessors, medical practitioners experienced with personal injury, judges experienced with civil damage and psychologists or psychiatrists (or both).

   **Recommendation:** That awards are on a civil damages/tort rules basis, and so the panel of assessors should include judges experienced in these matters and members of the medical profession). It is very clear that whatever the Government decides it is vital that some kind of appeal procedure is put in
place. Additionally, applicants should be able to re-apply if their health deteriorates for a review of their award if they wish.

5. Who should administer the payments?

The vast majority of those questioned would like their payments to be administered by the DWP, as recommended in Lord Archer’s report. Of those who did not want this payment route the next most popular choice was to be paid through the MFET/MFT and/or Skipton Fund or other vehicle.

Recommendation: To make payments via DWP. If this is not possible then a new vehicle for payments should be considered.

6. What should happen to the MFT/Skipton bodies?

We asked people who did not want the MFT/Skipton bodies used as payment vehicles, what should happen to these funds if they were not used. Here, there was an even split between those who wanted them retained in a supervisory role and those who wished their role to be concentrated more to social work.

Recommendation: It is clear from this that the majority of those questioned believe that these Trusts should have some kind of ongoing role. There is a general requirement for some sort of ongoing support body to be made available, so a method of achieving this is required.

7. Who should benefit from the scheme?

A substantial number of the community would like the scheme to include all those currently ‘on the books’ or known to MFT/Eileen/MFET/Skipton Fund, no matter where they reside. A significant number would also like the scope of the scheme extended to all UK Nationals who received treatment in the UK and include those who have been affected by this as an immediate relative (i.e. spouses/partners, dependent children and parents/siblings). We believe that both these wishes could easily be accommodated by Government.

Recommendation: That awards should be payable if infection or exposure is established via NHS treatment. If the application relates to an infectee who has cleared any virus, such as Hepatitis C, providing initial infection can be established by medical records, then they should fall under the provisions of these recommendations. Application should therefore be open to those who can establish that infection occurred under the NHS in the UK, irrespective of where. Existing MFT/Skipton Fund haemophiliacs/spouses registrants, to be used as the starting point.

8. Timescale

A significant number of people expressed a strong desire to see the scheme finalised as quickly as possible. Many of them felt that, having suffered physically, mentally, and financially for over twenty five years. They would very much like the chance to lead what is left of their life with some financial security and without the constant strain that campaigning has brought to them.

Recommendation: That a time frame is agreed on the processing and finalising of claims and assessments - 6 months maximum from the date of any initial claim.
9. Means-Testing

**Recommendation:** We very strongly recommend that entitlements should not be means tested, a point that had almost universal acceptance.

10. State Benefits

**Recommendation:** We very strongly recommend that awards should not have any impact on state benefits, a point that also had almost universal acceptance.

11. Future Health-Care Charges

The vast majority of those questioned expressed a wish for counselling to be provided, with the greater number of these asking for it to be fast-tracked, with waiting time of no more than a week. We believe this demonstrates the terrible psychological and emotional problems that people are living with as a direct consequence of their infections.

**Recommendation:** Those who have been infected should be exempt from any charges relating to their future health care. This should include priority access i.e. within one week, by whatever means, to appropriate counselling. This counselling should not be limited to any particular number of sessions. We would therefore urge the government to consider fast-track counselling as a matter of urgency, or to include an allowance within the financial package allowing individuals to fund private counselling as required.

12. Provision for insurance services.

**Recommendation:** Provision for Insurance Services needs to be made. This can be either by the Government paying the extra premium that infections have caused, or in the case of the un-insurable, acting as underwriter. A scheme similar to this is in place in Ireland, and so, it would be relatively easy to use the same insurer to set up this scheme in a short time i.e. maximum of 6 months from the date of agreement. The scheme should cover life assurance, medical insurance and any other form of insurance where premiums are loaded as a result of the infections received.

13. Patient Representatives

It is clear from the many exchanges we have had with people over the years that there needs to be greater direct patient involvement in the future care of haemophiliacs. This was backed up in Lord Archer’s report. The full involvement of patients in all decision making is widely seen as the most important lesson in terms of changing processes to build confidence for the future. If the misuse of Crown Immunity and the failure of the Medicines Act are also addressed then people will begin to feel that the relevant lessons have been learnt. Whilst we would like to see a body set up that is
similar to that described in Point 1 of the Archer Report recommendations, we believe that a large part of this could be achieved by the involvement of patients in the Haemophilia Alliance. How patient representatives are to be nominated can be resolved within a 6 month time frame. We also feel that it would also be useful to establish a Royal Commission to investigate the facts behind this tragedy to help ensure that lessons are learned and how the Medicines Act may need amending to incorporate advances made in organically derived treatments.

**Recommendation:** That the Haemophilia Alliance should be extended to include patient representation and that a Royal Commission should be established to investigate the facts behind this tragedy. It should also review the Medicines Act to ensure that it incorporates the advances made in organically derived treatments.

14. **Limits to Recommendations**

**Recommendation:** That these recommendations are limited to all UK Nationals (or foreign nationals domiciled in the UK) who received treatment in the UK via the NHS.

15. **Consultation**

**Recommendation:** No settlement should just be handed down without discussion. Government should bring forward a proposal and accept feedback on it, before it is implemented.

16. **Political Changes**

The commitment to resolve the outstanding issues needs to be formalised in such a way that any future change in Government will not put this agreement at risk.

We believe that these are the steps that will allow the majority of those infected to achieve closure. We would be available to discuss the potential scheme that the Government would put in place, ahead of its publication.

The Haemophilia Society, Manor House Group, and Tainted Blood.
Some Further Comments

We asked campaigners to add any further comments that they wanted taken into account. Here is a selection of those comments that we believe are representative of the common theme:

‘I believe anyone infected or affected by the scandal, should get compensation, and counselling. I get depressed quite a lot, this makes me irritable, and aggressive sometimes towards my wife and kids without meaning to. I believe counselling would help greatly with this.’

‘I lost my job a few years back after going on an experimental drug to try to clear the Hep C as the side effects were horrid, but I deemed it worth the go in the hope for a clear result, sadly this didn’t work for me and I still have the virus, but after losing my job, I also lost my house, which was repossessed and sold for a shortfall of £40000.’

‘I would really like to just be able to buy a house outright for my family. I cant hold down a full time job as sometimes I am too sick or too tired, too angry, too depressed, I was just before Xmas 2009 taken off Incapacity Benefit as I was deemed well enough to work…’

‘I have HIV and HEP C (HIV at aged 12) I was told I would be dead by 20. My school life was ruined, my job prospects were ruined, my health was ruined. I have psychological problems also. Please sort this mess out.’

‘I think all people affected by what happened should get looked after in what time we have left with each other our families and friends etc. No amount of money can savour or harbour life but it can ensure that the people we care for are cared for afterwards.’

‘I think the overriding principle of any settlement should be fairness. I also think a 6 – 12 month concluding period should be achieved as this has gone on long enough.’

‘We need to be compensated for the horrors we have been put through, and the nightmares that are still to come.’

‘As I see it any result to this problem will come down to Money… How much one person believes another is worth on paper and how much is good enough to be considered a fitting payment. Even if they know what they are willing to pay for a life (and I’m sure they do know) and you know what you are willing to accept…I’m sure whatever the outcome may be, it will never truly account for those who have already died or ever really take away the massive feeling of guilt over losing of a loved one because of you, the loss of the life you were not allowed to have, the relationships that failed or for the children that were never born to us, then if you add-in the physical/mental trauma, stress, fear, the isolation, the secrecy and the Many various humiliations we have had to endure due to no fault of our own… I could go on, you see even as I write these words they fall short of being the right words and they only convey a small glimpse into a world too difficult to explain on paper and on paper is where it will I’m sure this will all come to an end. These, I fear, are the individual nuances of the negotiations that do not transfer well to paper and could, if not careful, be lost.’

‘Compensation, admission of passing on these terrible diseases and an apology will bring some sort of peace of mind for those of us that are still alive for now and, for the families that have had
to deal with the death of loved ones. We would like to be treated the same as the general public, insurance for life and travel, equal medical rights, we have a right to live as normal a life as we possibly can maintain, while we have it.’

‘Let’s not forget most of us did have a fairly normal life (apart from the affects of Haemophilia), now most of us are suffering from the issues connected with Hep C and HIV.’

‘We must also not forget that the Irish system included priority medical cards. I have found through various treatments I have been on and the complications I experienced, that I could have done with one of these cards as when I asked for help, it was not forthcoming’.

‘Under no circumstances whatsoever should the Government even think about asking any of us to sign any type of waiver as they have done in the past.’

‘Please can we keep this as simple as possible, I don’t want the Government dragging this out forever.’

‘I don’t think it should be limited to Dependent children. In my case my father was infected when I was a teenager, I was told when I was 16 and then had to witness my father deteriorate before my eyes. Just because I was 8 weeks past my 18th birthday when he died, doesn’t mean I suffered any less than my younger brothers.’

‘We all need closure on this. I for one would so much like to be financially independent.’

‘The government should now do the decent thing and implement the recommendations of the Lord Archer report. Ending 20 plus years of poverty, hardship and uncertainty for all those affected by contaminated NHS blood products.’

‘Whilst I am happy with the level of care I receive at my Haemophiliac centre, the barbaric and insensitive way in which we were informed of our infections, at a very young age, should be noted and the trauma of that also taken in consideration.’

Widows, and family who have lost husbands etc should be included in any compensation scheme without any reference to cut of dates.’

‘I’m 28; I have severe haemophilia A, and am Hep C positive. There are a number of things I would not have had to go through in my life had the government’s decision to accept the tainted blood never taken place. Watching my mother cry at my jaundiced appearance as she walked into my cancer ward as my liver was fighting to keeping me alive during one of many chemotherapy treatments is certainly a scene burned into my retina…I can remember attempting to hand over change in a supermarket and when the girl caught a glimpse of my inflamed red hand pouring the change onto her outstretched palm, she quickly pulled it away… coins all over the floor…Watching my friends have lives, relationships, careers and even looking to buy property…. is difficult. I suppose I feel left behind. All I want is a chance to make a start. I feel the Archer Report’s recommendations go some way to giving me that.’

‘Their father would want me to fight on to secure their future as he always did. Justice for us all would perhaps give them some closure and help them move forward into the next phase of their
lives, and if they wish to use any monies received to go to University or fund any other career opportunities they chose would make him proud as he always was of them when he was alive.’

‘I would like to see a one off settlement that is fair to everyone including widows and children’.

‘…as a single mum I want enough money to buy a decent home so that my 12 year old son will always have a roof over his head. A sorry would be nice too’

‘No bits here and there, no begging for handouts. A final settlement for all.’