

**TaintedBlood's Response to the Final Report of the Independent Public Inquiry into Contaminated Blood and Blood Products, Chaired by Lord Archer of Sandwell**

On behalf of its mandated members, the committee of TaintedBlood would like to begin by offering our thanks to Lord Archer and his panel for voluntarily giving of their time to conduct this inquiry. We acknowledge that in the beginning it was only anticipated that their work would take three to four months, but in the end has taken nearly two years. Our thanks must of course extend beyond the current panel, to Lord Turnberg who was one of its original members but sadly had to leave because of a family tragedy. The inquiry came about following many years of campaigning by private and public figures, perhaps none more influential than Lord Morris, to whom we also offer our thanks.

The tragedy of contaminated blood and blood products has been dubbed by Lords Winston and reiterated by Lord Morris as: '...the worst treatment disaster in the history of the NHS.' It has killed, widowed, orphaned and destroyed the lives of thousands of people. In this, the 60<sup>th</sup> anniversary year of the NHS, we would like to pay tribute to all these people, in particular those who have fought for justice on behalf of those who can fight no more.

We at TaintedBlood appreciate the extent of the task undertaken by Lord Archer and his team. The history of contaminated blood and blood products is multi-faceted, extremely complex and has encompassed 7 Prime Ministers. It has fallen to 6 Secretaries of State for Social Services and 9 Secretaries of State for Health to deal with our on-going battle, along with ministers, MPs and Lords too numerous to name. It has been the subject of endless questions in both houses and has generated thousands of letters, e-mails and newspaper articles and, more recently, Freedom of Information requests. It has featured on every major television channel, most local and national and radio stations, and the story of our plight has been replicated around the globe. We at TaintedBlood, along with many other campaign groups vowed long ago never to give up the fight until we achieve justice, and so we again thank Lord Archer for attempting to finally bring us closure.

**Our comments on the content of Lord Archer's Report are as follows:**

We would like to express our appreciation at the panel's attempts to get to grips with the history of contaminated blood and blood products. We were fully aware of the limitations imposed on Lord Archer in terms of the ability to call witnesses. We note that this was as a direct result of the failure of the government to grant a public inquiry held under the Inquiries Act, 2005. We further note that because of this Lord Archer was unable to insist on witnesses giving evidence and this meant that there was no representation at the inquiry from the current cabinet or the Department of Health. However, we are conscious that Lord Archer was able to call on members of the legal profession, both past and present, to add weight to the campaigner's evidence.

We very much appreciated the sympathetic way in which Lord Archer and his panel handled evidence from those affected and infected. Much of this was harrowing and it took great courage for these people to give their testimonies.

*We are delighted that Lord Archer's report gives a detailed account of the events surrounding contaminated blood and blood products. In particular, we note that he has shown full awareness of the catastrophic effects that have been felt by the families involved and the need to address their continued suffering as a matter of urgency.*

**In particular, we would like to address the following points:**

**1. Use of Non-Consensual Research**

One of the most important areas of the Inquiry is the use of non-consensual research and the use of unethical trials:

*We are baffled to see that the crucial area of non-consensual research and the use of infectivity trials has been overlooked. There is sound supporting evidence to prove that the medical profession allowed unethical trials to dictate clinical need in the haemophiliac community.*

**Quote:**

*"ROBERT MACKIE: We discovered that an AIDS study was being carried out on me from March 1983. This AIDS study was, it seems, the beginning of many years of research being carried out on me without my knowledge or consent. My consultant was fully aware of the value to scientific endeavour of his Edinburgh patients, myself included and that I along with others were of value to him as a publishing scientist and potentially to global public health. The doctors wanted to find out if the spouses...this virus was going to be transmitted to spouses. That was their game."*

**2. Historical Situation: Failure of Self-sufficiency and Maladministration:**

The history surrounding contaminated blood and blood products is well documented in various books, Freedom of Information documents and various comprehensive timelines.

*We are pleased to see a most thorough account of the years leading up to the contaminated blood and blood products catastrophe. The report has not shied away from tackling the years of government maladministration and neglect. The report*

*makes mention of many important areas and we are particularly impressed with the veracity of the evidence on the delays in bringing Britain to a time when it was no longer dependent upon plasma-derived products. We note that the report recognises the on-going problems within the area of blood product production.*

**The report states:** *‘We are dismayed by the time taken by Government and scientific agencies to become fully alive to the dangers of Hepatitis and HIV infections, and also by the lethargic progress towards self-sufficiency in blood products in England and Wales.’*

**Quote:**

*“MR MOSSMAN: I firmly believe that all this came about because of the lack of investment into the self-sufficiency of the BPL labs at Elstree, and what sickens me and infuriates me: as a mild haemophiliac, I need not have been exposed to these filthy blood products.”*

*We were also heartened to see that Lord Archer’s panel have recognised of the years of maladministration of the UK’s handling of the repeated attempts at self-sufficiency in blood products.*

**Quote:**

*“SUE THREAKALL: If people had listened to Dr David Owen and if they had listened to the warnings which had started to filter out from America and they had listened to the warnings that were starting to go round in this country years before to try to make us self-sufficient in blood products, most of that problem could have been eliminated.”*

*We note that the report makes little or no reference to the use of UK prison blood nor does it mention blood from American GIs posted in the UK. However, the report makes frequent reference to USA prison blood. The report lacks a satisfactory discussion as to the reasoning behind failing to make use of plasmapheresis in order to improve the yield from voluntary blood donors – which would have provided the UK with an opportunity to attain self-sufficiency.*

### **3. Testing for HCV without Consent and the Withholding of Results**

Many persons with haemophilia and recipients of whole blood and blood components feel that they were inappropriately tested for Hepatitis C in the late 1980’s without ever being asked if they wanted to be tested or even being informed that they were being tested. Many were not made aware of the results of these secretive tests until many years after second-generation HCV screening was implemented in September 1991. Some discovered their HCV status by accident whilst looking through their medical notes or on transfer from one hospital to another.

**Quote:**

*“MR FIELDING: It came to light later on that I had been tested a few years earlier than when I was diagnosed with Hepatitis C. And I had two daughters between 1992 and 1993. So theoretically I could have infected two innocent young babies--*

*THE CHAIRMAN: Did you know you were being tested?*

*MR FIELDING: No.”*

*The very inclusion of this delicate testing issue in the report may mean closure for many individuals in our community. At the very least they will now feel that future generations may be spared what happened to them. However, we have to ask which ethical bodies approved these clandestine tests and what sort of government department would sanction these non-consensual HCV tests on persons with haemophilia whilst they were litigating against the Department of Health in 1989. This is surely a case for the Department of Constitutional Affairs to immediately investigate.*

*The report states: “It is hardly surprising that, since there had been litigation, entailing mutual disclosure of documents, there are suspicions that the authorities may have been aware that some patients had been tested for Hepatitis C, with positive results, of which they had not been informed by their doctors.”*

#### **4. The situation for Widows and the Bereaved**

*The report goes the full distance in recommending equality of treatment and adequate payment levels of the Skipton Fund ex gratia scheme for widows and the bereaved. TaintedBlood would strongly recommend that the government immediately redresses the anomaly in The Skipton Fund so that all widows whose husbands died with hepatitis C immediately receive both levels of payment. The numbers for this are finite, the money is already available and the administration is already in place. This would ensure a level playing field before a new formula for funding – hopefully parity with Ireland – was instituted.*

#### **5. Parity with Eire**

*We applaud Lord Archer for his brave comparative assessment of compensation and other measures using Ireland as an example. This will potentially mean as much as 10 times the amount of relief / restitution to our community as well as the inclusion of widows and others in the payments...*

**Quote:**

*“Carol Grayson: The decision of the UK Government not to provide recompense for haemophiliacs on a parity with Eire was based on the fact that the situation in Eire was different. This obstacle has now been*

*removed. We can say with confidence that the situation in Eire is no different to the UK. We have now clarified this with evidence from Irish lawyers and the Eire Government, who know their own situation far better than Lord Warner and have backed us in our fight for parity and justice”.*

***We strongly urge the Government to implement these logical and compassionate recommendations with the utmost urgency.***

## **6. The Fate and Long-term Funding of the MacFarlane Trust**

For many years now, the Macfarlane Trust has been aware that many registrants have been living in some form of poverty which neither the benefits system nor MFT (as currently funded) has been able to significantly alleviate. The original lump sum payments, which were relatively small, were based on a short life-expectancy of 5 years. For more than 20 years, beneficiaries have had to live on benefits, supplemented by modest monthly payments from the MFT. The Trust has never been given the resources necessary in order to give adequate support to bereaved families, despite the Trustees’ representations to Government on numerous occasions. Many registrants are unable to make provisions for their families in the event of their own deaths.

***During the Inquiry we heard from Mr Christopher Fitzgerald that the reality was that there had been no effective increase in the funds available to the MacFarlane Trust since 2003, and they were told not to expect any increase in 2008/2009 either. (This applies in the context of the Eileen Trust also). The situation for primary beneficiaries and registrants of the Trust can only worsen with the constantly rising cost of living –the effects of which are exacerbated, due to medical need / unique medical circumstances. The needs of the very special community of MFT beneficiaries are not being properly provided for since the MFT cannot meet all the need that is put to them. We are all too aware that discretion has to be applied and it is extraordinarily difficult for MFT staff and trustees to make these decisions. This ongoing situation must be looked at especially as we now have the situation where MFT beneficiaries no longer feel that approaching a charitable trust to "beg for support" is the way forward***

***We were therefore pleased to see that the future of the Macfarlane Trust and other agencies is a significant part of the Archer Report. We are pleased to see a thorough appraisal of long-term funding and a discussion of the possible solution of a lump sum to enable people to plan their lives and make choices to empower themselves to run their own lives. We have some misgivings about the proposal to make payments through the Department of Works and Pensions, since this still seems to implicate that people are in the position of receiving benefit payments as opposed to becoming financially independent.***

## **7. Inclusive Care through the Creation of a Formal Body**

In the Haemophilia Society's second submission to the Inquiry, it was suggested that a formal national Haemophilia Committee should be created on a statutory basis.

*We are encouraged to see that Lord Archer has taken this suggestion on board and recommended the formation of a statutory committee to advise Government on the management of haemophilia in the United Kingdom.*

## **8. Formal Participation in the Tender Committee**

The Haemophilia Society's second submission to the Inquiry made the recommendation that the Society be given a designated role in the offer and purchasing process for medical care and treatment of those with bleeding disorders.

*We are delighted that Lord Archer has seen the benefit to affording the Haemophilia Society a formal role in the tender process, as this would undoubtedly mean that in future there will be a commitment to fund the best available care for persons with haemophilia and other bleeding disorders. The interests of persons with haemophilia will be represented during the process of applying for and apportioning government funding for medical treatments and care.*

## **9. Access to Free Healthcare**

Along with the Haemophilia Society, Taintedblood would like to see free healthcare for all those affected by the contaminated blood disaster, and...

***Quote:***

*The UK Haemophilia Society: "People with haemophilia who have contracted HIV and/or hepatitis C through contaminated NHS blood and blood products should not have to bear the burden of paying for their healthcare."*

*We therefore applaud Lord Archer for taking a positive stance on this issue, and recommending access to benefits not freely available under the NHS. We very much hope that Government takes the necessary action to bring about this significant and much-needed move forward.*

## **10. Tracing and Testing**

TaintedBlood agrees with the Haemophilia Society that a full 'look back', along with new guidelines for the future, is essential if the public is ever to have future confidence in blood and blood products.

*We commend Lord Archer's stance on this issue and hope that the Government takes note and initiates action as a matter of urgency.*

## **11. Infection with Hepatitis C**

We know that all haemophiliacs who were treated with commercial factor concentrates during the 1970s and early 80s have been exposed to infection with the hepatitis viruses B and C and by the time heat treatment was introduced in 1985 (1987 in Scotland) some 4,670 of those had been infected with hepatitis C. This was not helped by the fact that the UK was one of the last countries in the developed world to introduce testing of blood donors for hepatitis C.

**Quote:**

*PAUL BATEMAN: "In 1992 I was informed at a routine hospital appointment by another haematologist that I had hepatitis C, but I was told not to worry about this because I had probably had it for a while and HIV would probably kill me a long time before hepatitis C would cause me problems."*

*We are pleased and reassured to see that the report makes the tragic infections with the hepatitis C virus one of its core issues.*

**Quote:**

*The UK Haemophilia Society: "The Government must conclude a financial settlement that will fully recognise the lost potential of people with haemophilia infected with HIV and / or hepatitis C and its effect on their current living standards. This should be a full and final settlement, which would replace the current arrangements."*

## **12. The Need for a Full Judicial Inquiry from Westminster**

We are gratified to see that the report shares our concerns regarding the historic needs for a full Public Inquiry:

**Quote:**

*"A full Public Inquiry into this issue should have been held much earlier to address the concerns of the haemophilia community."*

In April 2008, Nicola Sturgeon MSP, Cabinet Secretary for Health and Wellbeing announced to the Scottish Parliament that the campaign for a Scottish Judicial Inquiry had been successful.

**Quote:**

*"MR FRANK MAGUIRE: But I think it has to be said, and this is my view based on Lord Mackay's judgment, that just now, the Department of Health and the ministers and the Westminster are acting unlawfully in not holding an inquiry, contrary to article 2."*

Whereas a full public inquiry under the Inquiries Act 2005 had always been one of our aims, we can also see the benefits from not having to go down this route. If such an inquiry were to take place it would inevitably mean that many more people would die before its conclusion.

We are confident that, if Lord Archer's recommendations were to be fully adopted by Government, and implemented as a matter of urgency, the need for a full public inquiry and the huge expense it would entail could be avoided. We recognise the fact that this would mean that not all stories would be told and that many potential witnesses would never testify, but for those with shortened life-expectancies we recognise that this would be a prudent move.

### **13. Implications of Legislation**

It is important that legislation, in particular both UK Statute law and European law is dealt with and referred to wherever possible.

*We are therefore encouraged to see some appropriate references to the law, both past and present. Examples include: Crown Immunity and The Medicines Act 1968.*

**Quote:**

*"MR VIJAY MEHAN: Just going back to the Factor VIII litigation, was it not contemplated that you could perhaps bring it under the Supply of Goods and Services Act which was 1974, only against the pharmaceutical companies? Because if there was no issue of causation, the issue of -- well, you would have had a successful --"*

### **14. The Impact of vCJD and the Handling of "At Risk" Status**

More than 4,000 persons with haemophilia or bleeding disorders in the United Kingdom received around 101 batches of NHS factor VIII, factor IX, or antithrombin III plasma products, which were subsequently deemed to be potentially contaminated with vCJD because the products were manufactured from plasma donated by people who later went on to develop variant Creutzfeldt-Jakob disease.

People with haemophilia and other bleeding disorders are now deemed to be at increased risk of carrying variant Creutzfeldt-Jakob disease (vCJD) and since 2004, have sadly been considered "at risk" of vCJD for Public Health purposes and have been entered onto the 'At Risk' register by the Health Protection Agency (HPA).

**Quote:**

*“BRUCE NORVAL: I still feel to this day that I am treated like a second class citizen and politically disenfranchised with my own country. What I don't understand is that there is no recognition for the need for support, there are certain areas for funding. You have some funding for a social worker for HIV in one centre, but there was no support for hepatitis C victims. There was no psychological back-up after the CJD notifications went out even though it was pretty clear that was going to have an impact.”*

**Quote:**

*“ANDREW MARCH: We know that there are new blood tests as I have said already, and that different companies are making them... I tried to broach the subject with my consultant recently and I got stone-walled and basically told that there is no test. Go away and be quiet. I would much rather a situation where we are included in the consultation process, with regular updates of where they are with these tests and certainly if there is any possibility at all that retrospective frozen blood samples or sera of haemophiliacs are being used to validate these tests because that is just unacceptable.”*

***We feel that the report is not thorough enough on the issue of the threat of infection from vCJD. This is especially hard to reconcile with the Inquiry's remit, since it stated that they were to: ‘...investigate the circumstances surrounding the supply to patients of contaminated NHS blood and blood products.’ We therefore feel that it would have been more appropriate to have covered the impact of vCJD and, at the bare minimum, an investigation into how vCJD “at risk” status has been dealt with in relation to persons with haemophilia.***

## **15. Access to Insurance**

Haemophiliacs and their families, often living with multiple viruses find it virtually impossible to access insurance services.

***We are heartened to see that Lord Archer addresses this issue in his report and hope that the Government will take note and compensate accordingly.***

## 16. Funding for the Haemophilia Society

Many of us at Taintedblood have a long association with the Haemophilia Society, and we find it reprehensible that the Government does not afford this vital organisation adequate funding.

*We therefore fully support Lord Archer's stance on this issue.*

*'We consider it vital that the Government should secure the future of the UK Haemophilia Society by adequate funding. This should be seen as a matter of urgency.'*

## 17. Counselling

In the early days of peoples' infections, counselling was often not offered at all:

*"ANDREW EVANS: It was dealt with on a purely medical basis. There was no counselling offered. Obviously I didn't find out until a good five years after I was infected but from what my parents have told me and you have to remember that I am really remembering a lot of this through them, through my mother, really, because my father is no longer with us, but there was no counselling and support offered for relatives of children at that time, and then my parents at the time when they told me, being left to, in effect, counsel me without having dealt with the issue first themselves."*

This meant that, not only were people never afforded the chance to benefit from the skills a qualified counsellor is able to offer, but worse than that the advice given at the time was so inadequate that other people's lives were put at unnecessary risk:

*"COLETTE WINTLE: The first time I was tested for hepatitis C was in 1991, several months after I got married. I was asked to go to the London hospital to have a blood test and, as previously stated, I was not offered any counselling before my husband and I got married so there was no opportunity to discuss implications of having the virus or what risks that posed to my husband, and the subsequent havoc that the disease was going to cause to my health and my family life."*

*"ALAN BURGESS: I was numb with shock but as my wife and I were unsure of what the consequences were we asked for advice but were told I looked okay so there was no need to worry. And at no point were we offered any form of counselling. So we were basically left on our own, a very bewildered couple."*

On many occasions the advice given simply heaped more damage on that already done:

*"ROBERT MACKIE: The circumstances in which I was informed of my HTLVIII status in 1987 are unforgettable, and when my wife and I attended the appointment my consultant asked my wife to leave the room. When we refused he left us alone to discuss her going. When he returned five minutes later and she insisted she stayed he showed his displeasure. He then went on to ask the questions -- have I used intravenous drugs, slept with any other women or slept with any other men -- and he then went on to tell us that I was infected with HTLVIII and that he had met the donor of the infected blood donation, that the donor had been a homosexual and that he was dead. "That was the end of the meeting. This flippant remark was stated to us after it was written and discussed in July 1983 that predicted mortality is 100 per cent in 25 months for haemophiliacs. The minute this meeting ended is a time that we began to live a life full of secrecy and lies. Neither at this meeting nor at any time afterwards was an HTLVIII test or counselling offered to my wife."*

At its worst, advice given was so poor it could be described as disgraceful:

*"THE CHAIRMAN: Did you ever receive any counselling?  
MRS BULLOCK: No. One doctor suggested that a few glasses of wine did not do any harm and that was six months before he died, of liver failure."*

Doctors' attitudes were often casual and uninformed...

*"THE CHAIRMAN: To your knowledge, was he ever offered counselling?  
SUE THREACKALL: When he was told that -- first informed about his positive test, he was told: we do not really know what it means, we suggest you use a sheath when you have intercourse. Don't have a baby for two or three years. You may be lucky, you may be inoculated against it because of the way you were given the virus in the first place."*

...and often cruelly dismissive:

*"JANET SMITH: That was the first time we ever knew he had hepatitis C. And this was such a shock that it was the first time it was mentioned to us. When we got to the hospital I actually asked when Colin was infected. The doctor just shrugged his shoulders and said it could have been his first treatment. I then asked what had actually killed him -- was it AIDS or hepatitis C? And he just looked at me and said it could have been any one of them and then we were asked to leave. So why were we not even told*

*that Colin had hepatitis C? Because we went home absolutely dumbfounded, because it was never discussed, we never had counselling..."*

It is clear that in the early days there was an appalling lack of funding which could have been allocated towards this issue:

*"PROFESSOR IAN FRANKLIN: In 1985, the central Government provided funding to haemophilia reference centres for additional counselling but, we were not a reference centre so we didn't get any of that."*

***However, the situation has changed little over the years and people still struggle to obtain good counselling services and often have to self-fund it. We are therefore delighted to see that Lord Archer has made recommendations for cards entitling the holder to benefits not freely available under the NHS in his report, and urge Government to take these suggestions on board and act swiftly.***

## **18. Compensation**

No-one can bring back those we have lost and nothing can lessen the pain felt by those left behind. It is, though, possible to ease the burden on those still living, often with multiple viruses, by providing a fair and reasonable financial settlement. Many of us have fought this issue for over twenty-five years now.

***We therefore applaud Lord Archer for tackling this delicate issue head on and for his recommendations that direct financial relief should be provided for those infected, and for carers who have been prevented from working. We are particularly pleased to see that Lord Archer recommends parity with Ireland, as this is something we have long campaigned for. We urge the Government to take heed and act swiftly.***

## **Conclusion:**

Finally, we at TaintedBlood would like to remind Government of the eight accusations we made at the opening of the Inquiry:

- 1: Gross Maladministration, Systematic Failure and Sheer Neglect
- 2: Conducting Unethical Trials and Allowing Research to Dictate Clinical Need
- 3: Aiming Infectivity Trials at Children and Disregarding their Human Rights

- 4: Ignoring Warnings and Failing to Take Adequate Preventative Measures
- 5: Failing to Learn Lessons and Introduce Safer Products such as Recombinant Factor
- 6: Procrastinating over early HIV Tests due to Greed & Intellectual Property Rights
- 7: Knowingly Withholding HCV Status Results & Placing Partners at Avoidable Risk
- 8: Deliberate Obfuscation by Vanishing Evidence such as Signed MFT Waivers

**We stand by these accusations fully and would urge Government to take them on board, along with Lord Archer's report. We would ask that, having done this, they act with humanity and compassion and assist us in bringing about an end to a quarter of a century of campaigning. Government alone has the power to bring an element of peace to so many shattered lives and to ensure that never again do members of the British public suffer as we have done as a result of something which we believe was wholly avoidable. It is never too late to put things at least partly right, and we would urge that this Government makes every effort to do this.**

*Despite our reservations in some areas we commend Lord Archer for this fair and comprehensive report. We are delighted that, under the constraints he was forced to work with, he and his panel have fully investigated and understood the issue of contaminated blood and blood products. We are particularly pleased that he has realised the ongoing effects on our community after so many years and that he has suggested ways in which our burden is made easier to bear.*

*We would strongly recommend that the campaigners are allowed to work with Government in adopting Lord Archer's recommendations, in order that all areas are addressed thoroughly and accurately.*

**The TaintedBlood Committee**

## Some Useful Facts and Figures:

- Just over **1,200** British haemophiliacs were infected with HIV, the virus that leads to AIDS. Of these, roughly one-quarter, (300-330) remain alive. In terms of infection with HIV/AIDS, this represents a **75%** mortality rate in the haemophiliac community.
- **5,000** British haemophiliacs were also infected with Hepatitis C through their NHS treatment.
- To date, almost **2,000** people have died as a result of their exposure to contaminated NHS blood and blood products.
- Whilst the Archer Inquiry's final report was being prepared, there have been **30** deaths in our community.
- **170** non-haemophiliacs were also infected with HIV following transfusions.
- There are at least 41 infected intimates/partners currently registered with the Macfarlane Trust.
- Over **200** non-infected widows, a small fraction, are in contact with the Macfarlane Trust.
- There are **10** orphans among the dependent children currently receiving care from the Macfarlane Trust. Their average age is just 14½ years.
- To top all this, more than **4,000** persons with haemophilia or bleeding disorders in the UK received batches of NHS factor VIII, factor IX, or antithrombin III plasma products which were subsequently deemed to be potentially contaminated with variant Creutzfeldt-Jakob disease (vCJD).
- On Sunday 15<sup>th</sup> February 2009, it was reported that an elderly person with haemophilia was found to have evidence of the infection that causes variant Creutzfeldt-Jakob Disease (vCJD) in his spleen at post-mortem. Although he died of other causes, this is the first known case of vCJD or the presence of the abnormal prion in a haemophiliac who had received vCJD-implicated plasma products which were made from the blood of a donor who went on to develop vCJD.