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Amendment 133

Moved by **Lord Morris of Manchester****133:** After Clause 32, insert the following new Clause—

"Committee to advise on treatment of haemophilia

(1) The Secretary of State shall by regulations establish a Committee to advise on the treatment of haemophilia in the United Kingdom.

(2) The Committee shall in particular provide advice on—

(a) the selection, procurement and delivery of available therapies for haemophilia patients;

(b) patients accessibility to treatments for haemophilia or any conditions which arise from consequent haemophilia therapy;

(c) the financial and other needs of haemophilia patients.

(3) The membership of the Committee shall include—

(a) specialist haemophilia clinicians;

(b) representatives from the Haemophilia Society;

(c) representatives from the Department of Health;

(d) representatives of haemophilia patients, through nomination by the Haemophilia Society and other bodies working to support the haemophilia community.

(4) The Secretary of State shall consult the Committee before making substantial changes in policy regarding the treatment of haemophilia patients and before introducing legislation which affects them.

(5) Regulations made by the Secretary of State under this section are—

(a) to be made by statutory instrument, and

(b) subject to annulment in pursuance of a resolution of either House of Parliament."

Lord Morris of Manchester: At last, completion of the Bill's Committee stage is at hand. For one dread moment, such was the heat generated by the debates on tobacco, I thought that we might all go up in smoke; but mercifully, due not least to the customary fortitude of my noble friend Lady Thornton, we have survived to address now the urgency of the needs of a small community of congenitally disabled people who, in the words from the scriptures, are living in sorrow and acquainted with grief.

I have interests to declare, not pecuniary, as president of the Haemophilia Society and architect of the independent public inquiry, headed so admirably by my noble and learned friend Lord Archer, into NHS-supplied contaminated blood and blood products, some of whose recommendations could be implemented by acceptance of the new clause, either now or on Report, pending fuller debate and further action on its findings as a whole.

I am most deeply grateful to my noble and learned friend and his colleagues in the inquiry team, Dr Norman Jones and Judith Willetts. Their report, exhaustively researched, is one also of excellent integrity and humane concern for arguably the most stricken minority in Britain today. I warmly acknowledge, too, the help of my noble friend Lord Turnberg who, as immediate past president of the the Royal College of Physicians, served the inquiry with such skill and commitment until he and his wife Edna were so tragically bereaved.

When I set up the inquiry two years ago, 1,757 haemophilia patients had already died from being infected by their NHS treatment with HIV and/or

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hepatitis C. The death toll has since risen by more than 200, and many more are left terminally ill by what my noble friend Lord Winston, vice-president of the Haemophilia Society, has described as the worst-ever treatment disaster in the history of the National Health Service.

Yet the grievous death toll is not the whole story; the haemophilia community suffers privation at a depth that most other people can barely imagine. I had a letter yesterday from a friend of a haemophilia patient infected with hepatitis C, which described his plight. He is uninsured due to the prohibitive premiums imposed by insurers on people with his condition. He can no longer work full time and his income is in sharp decline. Travel and other costs are becoming too high for him to cope with, and a mortgage deal is out of the question. In the noble tradition of Good Samaritans, the man who wrote to me has himself been helping his friend financially, but now he, too, is facing the loss of full-time employment. This is but one example of the urgency of the need now for purposeful action on the Archer report, of which approval of this new clause would be a clear signal to the haemophilia community that at long last its plight has been recognised at Westminster and in Whitehall.

For parliamentarians, there can be no higher duty than that of ensuring just treatment for those afflicted and bereaved by contaminated and life-threatening medication supplied by the state, and the emphatic backing of the report's recommendations by the mass media as a whole shows how clearly that duty is understood by the people of this country. It was just as clearly understood, too, by my right honourable friend Harriet Harman MP, Deputy Leader of the Labour Party and Leader of the House of Commons, when speaking on 5 March. Already having thanked my noble and learned friend Lord Archer, for his "important work", she told my honourable friend Dr Brian Iddon of her,

"congratulations to the campaigners",

on having,

"brought to the public's attention the injustice that they have suffered",

from contaminated NHS blood and blood products. She also made it clear to the House of Commons that:

"The Government will respond shortly".—[*Official Report, Commons, 5/3/09; cols. 993, 999.*]

Thus the Haemophilia Society now looks forward to a positive response to the landmark report that she so fulsomely welcomed.

7.15 pm

There are two other issues to which I must briefly refer. The first is the sombre threat now of a third scourge facing the haemophilia community. I refer to the increasing number of haemophilia patients known by the Department of Health to have received blood from donors who subsequently died of vCJD, and the recently reported case of one hepatitis C-infected patient, a post mortem on whom revealed vCJD in his spleen. I was informed more than once on the authority of the Chief Medical Officer that the risk for recipients of blood donors who subsequently died of vCJD was purely "hypothetical"; but that demonstrably is not the case now.

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Is donated blood currently being screened, or filtered to remove vCJD infection? If it is not, can my noble friend in replying to the debate say what protection is in place to safeguard recipients of donated blood? I understand, and my noble friend will confirm whether it is so, that technology is now available to remove by filter the abnormal prions which are the causative agent of vCJD and that it has passed EU-wide safety testing and clinical trials as required for its use in the UK. The haemophilia community, like Members of both sides of both Houses of Parliament, are anxious to secure ministerial assurances of urgent and effective action in this policy area, and I look forward to my noble friend's response to the questions that I have raised.

The other issue to which I must finally refer is that of Crown immunity, on which the Archer report raises in commenting on behaviour of the Blood Products Laboratory (BPL). The report says:

"In July 1979, the Medicines Inspectorate visited BPL. They reported that the buildings were never designed for the scale of production envisaged. They commented: 'If this were a commercial operation we would have no hesitation in recommending that manufacture should cease until the facility was upgraded to a minimum acceptable level.'"

The report then says:

"BPL was rescued by Crown Immunity",

and goes on to say that,

"the existing plant continued production, relying on Crown Immunity to dispense with all the requirements of the Medicines Act, but was able to meet only about 40 per cent of the national requirements",

Surely, words have lost their meaning if this does not mean that by the use of Crown immunity, a relic of feudal England, the lives of countless haemophilia patients were blatantly and gravely put at risk.

In this House on 10 March, the noble Lord, Lord Darzi, responding to me in exchanges about thalidomide, referred to,

“the tremendous amount of work that has gone into the marketing, testing and regulation of drugs, as encapsulated in the Medicines Act 1968, from which society has benefited greatly”.—[*Official Report*, 10/3/09; col. 1059.]

There could be no clearer text for describing the enormity of the use by the BPL of Crown immunity to dispense with all the requirements of that renowned and vital statute. I beg to move.

GRO-A I welcome and support this excellent amendment tabled by the noble Lord, Lord Morris. It is late, so I will attempt to get my words out quickly. The noble Lord, Lord Morris, has been a vigilant campaigner on behalf of people with haemophilia, especially those affected by contaminated blood products. He is to be applauded for calling the independent public inquiry, chaired by the noble and learned Lord, Lord Archer, which reported last month.

I declare an interest: my first husband, **GRO-A** and his **GRO-A** died as a result of receiving contaminated factor VIII blood products. **GRO-A** was 34 years old when he died and, at the same age, I became a widow. The scandalously slow reaction by previous Governments to safeguard blood products imported from the United States meant that

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we failed to protect nearly 5,000 people who died or are now living with HIV/AIDS, hepatitis C or, now, CJD.

The amendment proposes establishing a committee that will go some way to righting a great wrong which was done to those people. It is not a big initiative—it is just a committee—which would be a small, uncostly affair. The committee would not only improve the care of those who have suffered from the blood scandal, it would also help thousands of people with haemophilia who, with the right treatment, could lead long and active lives, working and building families. They are great when they have their treatment. You would not even know that they have a disability. Finally, as I have often said in the past, those with the most expertise of long-term conditions are those who experience them. I welcome, under subsection (3) of the proposed new clause, the holistic spread of the proposed commissioners; namely, charity supporters, Department of Health officials and, most importantly, the patients.

Every year on the anniversary of my husband's death, I visit the church of St Botolph without Bishopsgate in the City of London. At the back of the church is a small memorial book, which names those haemophiliacs who have died as a result of contaminated blood products. Every year, new names appear. Every year, haemophiliacs living with the consequences of lethal treatment—it was lethal treatment—require the very best information, advice and support. The proposed committee could provide that help. The Government have this opportunity to show that they recognise the extraordinary plight of haemophiliacs and I hope that they, and Members of the Committee, will feel able to support this amendment.

Baroness Barker: At this late hour, it would not be right to go into the many issues raised in the Archer inquiry. It is a very good report, which deserves serious and detailed consideration by this House. If it has established one thing, it is that people from all political parties were in different ways involved and that some have taken responsibility. This is not a partisan issue. I would suggest that it is an issue that the House of Lords is well placed to look at in some depth. I do not want to dishearten the noble Lord, Lord Morris of Manchester. I am not sure whether his proposal for a committee is right, but I am willing to listen to the Committee on that. What I am most concerned about is that the Government's response should be timely and appropriate. It is a great shame that the Government did not contribute to the inquiry chaired by the noble and learned Lord, Lord Archer, but they are under an obligation to respond in a timely fashion. The government response perhaps needs to be in two parts: one an urgent response to the needs of people who are currently living with the consequences of being given these blood products, whose needs are urgent and serious, and the other on the wider question of what we should learn from the inquiry. That response would be much longer and more detailed.

We would do well to consider things that happen in other healthcare systems, particularly the response in the American healthcare system, although it is an entirely different system, and what should happen in our healthcare system is not the same. Many deep

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questions of policy and practice emerge from the report of the inquiry chaired by the noble and learned Lord, Lord Archer. They deserve to be looked at, but let us not use them as a reason to delay responding to the urgent needs of people who need help now. Similarly, let us not use the urgent needs of people now as a reason to give a cursory response to those quite deep questions.

Earl Howe: I shall be very brief, as we are up against the clock. I hope that we will have a constructive reply from the Minister this evening in so far as she has time to deliver one. I understand that the Government did not provide witnesses to the inquiry chaired so ably by the noble and learned Lord, Lord Archer. That was regrettable. I join the noble Baroness in congratulating the noble and learned Lord on an excellent and thorough report. Great credit is due to him, his colleagues and all those who gave evidence to him. One of the things that I have learnt from the report is that there are too many haemophilia patients currently suffering hardship and serious distress as a result of this worst of all healthcare accidents in the history of the NHS. The Government have a moral obligation to give careful consideration to the report and to respond to its recommendations for the sake of those patients.

Baroness Masham of Ilton: I declare an interest as a vice-president of the Haemophilia Association. This seems to be a reasonable amendment. People with haemophilia have had the most unfortunate time over the years since the emergence of HIV/AIDS. In the early years of HIV, it was found that 75 per cent of haemophiliacs at the Newcastle upon Tyne unit developed HIV, and many of them have died. Hepatitis C was also found to be a problem. So was variant CJD, and nobody knows whether it will present itself and to whom. It has been horrific for people who have died from CJD and for their families.

Safety in blood and blood products is of the utmost importance. While I was visiting a haemophilia unit in Leeds, the telephone rang. It was a teacher from a school asking if a haemophiliac boy could play football. There are so many questions to be asked and answered. A united committee could give support and information to those involved with this challenging speciality, which needs all the support it can get. This amendment may be the last on the Bill, but this is an important issue. The work with prions needs top scientists to find a way of protecting everybody from the dangers of contaminated or tainted blood. It could affect anyone at any time.

7.30 pm

Baroness Thornton: The Committee is supposed to finish in one minute.

Lord Rea: I have a quote from the report, which sums up the problem in a nutshell. Page 105 states:

"We must now look to the future. We cannot undo the damage done, nor turn back the clock to take a closer view of those past events and decisions. We must address the ongoing needs of those affected and consider how the state can ensure these citizens are recompensed".

This amendment does just that.

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Baroness Thornton: I regret enormously that we could not have at this stage of the Bill the full discussion that this report merits, but self-regulation rules in your Lordships' House, including in Grand Committee. Noble Lords must have been aware of that earlier this afternoon.

Amendment 133, laid by my noble friends Lord Morris and Lord Corbett, is based on a recommendation made by the noble and learned Lord, Lord Archer, in his recent report, published on 23 February. The report, as we all know, considered the supply of virus-contaminated blood and blood products, and its devastating effect on the haemophilia community in particular from the early 1970s until tests became available for hepatitis C and HIV.

Noble Lords will be aware that my noble and learned friend's report is a wonderful document. I warmly thank him again, and my noble friend Lord Morris, for their work on behalf of haemophilia patients and their families. We recognise that the lives of many people have been seriously impaired and appreciate that noble Lords wish to take every opportunity to remedy this situation as far as they are able.

The establishment of a statutory committee is one of a number of recommendations made by the noble and learned Lord, Lord Archer. The Government take the report very seriously. We are giving careful consideration to all the recommendations. In light of this, it would be premature to implement any one of the recommendations before we have had time to consider the implications. However, some feedback from the Government on this matter is entirely possible before we reach the next stage of the Bill, which I hope that noble Lords will take into consideration.

My noble friend asked about vCJD screening tests. He is quite correct that no screening test was available. Getting a validated screening test is a priority. Prion filters are available, which we are testing with all speed. Those tests are still under way. Addressing this situation is a priority. We are taking the matter very seriously indeed.

There is no doubt that this group of patients has suffered tragic consequences as a result of these serious infections. It is important to ensure that the patients concerned and their families are properly supported, and to act to reduce as far as practically possible any future risk to patients who need blood and blood products.

I am sorry that we are unable to consider the matter further. I suspect and hope that we shall have a much longer and more serious debate on aspects of the report in the House. I have answered one question; we have dealt with it very briefly. That is not a satisfactory way of dealing with the important report of my noble and learned friend. However, until all its aspects have been considered, I would ask my noble friend to withdraw his amendment.

Lord Morris of Manchester: This is not the moment to press the amendment, to which we can of course return on Report. No effort will be spared in doing everything that parliamentarians can do to vouchsafe full implementation of the Archer report's recommendations. Naturally, I deeply regret that there has not been time even for the noble and learned Lord, Lord Archer, to

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speak in the debate. All of us want to say to Peter that he is held in high admiration, and we shall do our very best to see that justice is done to his exceedingly helpful and humane report. I beg leave to withdraw the amendment.

Amendment 133 withdrawn.

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Clauses 33 and 34 agreed.

Schedule 6 agreed.

Clauses 35 to 37 agreed.

Bill reported with amendments.

Committee adjourned at 7.35 pm.