

**LETTER AND SET OF QUESTIONS TO
THE MINISTER OF STATE FOR PUBLIC HEALTH
PROTECTION
DAWN PRIMAROLO M.P.**

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Rt. Hon. Dawn Primarolo M.P.
Minister of State for Public Health Protection
Richmond House
79 Whitehall
London SW1A 2NS

5 March 2008

Dear Minister,

I am a trustee of the Macfarlane Trust and have been for almost 2 years.
I was also appointed, a year ago, by the then Secretary of State, to the Board of the Eileen Trust.
I am a solicitor by profession and the son of the late Lord Mishcon, who sat for many years on Labour's front bench in the Lords as Home Affairs spokesperson and shadow Lord Chancellor.
I am currently doing a dissertation for a Masters degree in Voluntary Sector Administration at London South Bank University.

The title of my dissertation is:

The Strategic Challenges Facing the Macfarlane Trust: the effects of demographic change and lack of government funding on haemophiliacs infected with HIV/Hepatitis C by NHS administered contaminated blood products.

I have the full backing of the Boards of Trustees of the Macfarlane & Eileen Trusts for this dissertation and have sent out a detailed 18 page questionnaire (with 69 questions) to all surviving registrants of the Trusts (some 425) to try and ascertain the changes in their circumstances and their current and anticipated needs.

I would very much appreciate the opportunity of an interview with you for my dissertation, the results of which I would hope would inform both Boards of Trustees and, as importantly, you and your Department. The questions I would propose asking you are in respect of the Macfarlane Trust only and are to be found on the attached sheets. I anticipate that the interview should take no more than 30 minutes and I propose to record the interview and transcribe it afterwards.

The dissertation needs to be finished by the end of April. Whilst my preference would be for an interview as soon as possible and before 21 March, I appreciate how busy you must be and that you might prefer to provide a written response to my questions. I very much look forward to hearing from you with your agreement to be interviewed and a proposed date, time and place.

Yours sincerely,

GRO-C

Russell Mishcon

Minister

Preamble

Your Department has responsibility for the nation's public health and is the sole funding source for the Macfarlane Trust, a charity established by the Government, whose objects are "to relieve those persons suffering from haemophilia who as a result of receiving infected blood products in the United Kingdom are suffering from Acquired Immune Deficiency Syndrome or are infected with human immunodeficiency virus and who are in need of assistance or the needy spouses parents children and other dependents of such persons who have died".

Your department, in addition to being the sole source of ongoing funding for the Macfarlane Trust, has in the past provided ex-gratia capital sums to be administered to registrants by the Trust in a prescribed manner. The first was an interim measure providing a fixed sum of £20,000 to each registrant; the second provided a range of payments from £21,500 to £60,500 dependent upon individual circumstances, such as age, marital status and number of dependents. But this last payment (£24.5m. to be divided amongst some 1,230 people) was back in 1991, when it was a condition of payment that the then existing litigation was compromised and waivers were signed in respect of future litigation.

Given that it was the recognised belief on both sides that no registrant was likely to live for more than a few years i.e. much beyond any outcome of the then ongoing litigation, it is my understanding that such payment was not intended by the Government as a compensation payment (liability was not admitted) but as a hardship payment. Nearly 20 years on from that last capital payment, some 370 original registrants of the Macfarlane Trust (and some 40 infected partners) survive. My research indicates that their hardship and that of their dependents is on-going, and getting worse, and is likely now to last for many more years.

Questions

As the last capital payment was made almost 20 years ago to alleviate hardship, will you, as Minister, give serious consideration to a further capital payment being made to alleviate the existing hardship, which might allow surviving registrants to provide for their own and their dependents' future with a degree of financial independence?

The last capital payment, perhaps not surprisingly, clearly discriminated against young people, in view of their then life expectancy (many were teenagers or younger when the payment was made). A considerable number have survived and now have a life of sorts ahead of them; some are married and some even have children. Is there not a special case for providing an additional capital sum to this particular cohort, with a view to empowering them and enabling them to gain some financial independence, and thereby escape the benefits trap?

The Macfarlane Trust submitted to your department in 2006 a detailed Business Case for substantially increased annual funding (to more than a doubling of the

existing amount) based upon a long-term review by an independent consultant, funded by your department. The Business Case also called for a further substantial capital payment for registrants.

No substantive response was ever received by the Macfarlane Trust; more importantly, there seems to have been no rebuttal of the arguments put forward. Can you explain why this happened and, if not, will you personally review the matter?

In the light of your department's apparent refusal to recognise the Business Case, and in the acknowledgement that the department is the sole source of funding for a charity established by the Government, what strategy or strategies do you expect the trustees of the Macfarlane Trust to adopt to discharge their duty, as charity trustees, to their community of care, when my research shows that it is their considered judgement that your department is providing insufficient funds for them to discharge that duty?

I assume that you are aware of what other governments have done in making more adequate provision for those in similar circumstances in their respective countries.

I am thinking of Eire, Canada and Israel as examples.

Judge Krever wrote in the 1997 report into the Canadian Blood Service, which was named after him:

'The compassion of a society can be judged by the measures it takes to reduce the impact of tragedy on its members. No amount of money can make up for the pain, suffering and premature death of those infected with HIV, Hepatitis C or any other blood related injury. The financial burden of living with HIV or other blood related illnesses can, however, be quantified for the purpose of providing financial assistance to injured persons or their families.....'.

What criteria does your department use to quantify, evaluate and cost 'the financial burden' and needs of the registrants of the Macfarlane Trust and of their dependents?

I would be interested to have your comments as to why, in comparison to other countries, the UK Government appears to have such little compassion (using Judge Krever's 'measure') for those affected by this tragedy, which has been described by Lord Morris and Lord Winston as 'the worst treatment disaster in the history of the NHS'.

If you are familiar with the current medical prognosis of those surviving haemophiliacs, co-infected with HIV and Hep C, as I would hope you are, would you not agree that this requires not only more compassion but substantial, additional financial assistance?

Stigma still plays an important part in the lives of people suffering from HIV, affecting their social life, psychological welfare and, importantly, employment. Haemophiliacs were innocent victims of such infection and yet they suffer the consequences of the same stigma, perhaps more so because they are mainly

heterosexual and not drug abusers.

Does this not add to the responsibility of the Government to do more for them?

Can you enlighten me as to what the Department of Health knew (in 1991) concerning Hep C infection that was not in the public domain, because the waivers, that were required by your department to be signed in respect of future litigation from recipients of the 1991 payment, referred to hepatitis viruses, and no registrant, at that time, so it appears, had any knowledge that they had been infected with such a virus, actually Hepatitis C?

Would you not agree that most people under sentence of an imminent death (the then perceived outcome of their condition) would sign such a document (the waiver) in return for what might then seem a substantial amount of money?

The Department has chosen not to be represented at or to give evidence to the Archer Inquiry. Are you able to indicate whether you, as Minister, intend to give due consideration to any recommendations that might come out of Archer?

Finally, Minister, as some of your predecessors have consistently said that the Trust's registrants are regarded by the Government as a special case, to be reviewed appropriately, what message do you have for the registrants of the Macfarlane Trust and their dependents and for the widows and dependents of now deceased registrants about their future?