

## THE MACFARLANE TRUST

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CF/MH/dh

Rt. Hon Dawn Primarolo MP Minister of State for Public Health Protection, Department of Health **Richmond House**, 79 Whitehall. London SW1A 2NS

I am writing to welcome you on your appointment as Minister of State for Public Health Protection. I have written in similar terms to the incoming Secretary of State.

May I wish you every success in discharging the heavy burden of responsibility you are undertaking to the whole community in respect of public health protection. At the same time may I draw your attention to one small but very special part of that whole, the community of care whose needs the Macfarlane Trust is charged to relieve.

The Macfarlane Trust was established as the Government's response to the very special and tragic circumstances of those persons with haemophilia who were infected by the ational Health Service with the HIV virus by transmission of contaminated blood roducts. The Macfarlane Trust seeks to provide relief to those victims and their families with funding provided by HM Government through the Department of Health's budget.

Your predecessors have repeatedly made statements recognising the hardship and great distress that those victims and their families have suffered, coupled with expressions of deep regret and commitments to provide the finances which the Trustees need for the Trust Fund. Notwithstanding those commitments, a submission for substantially increased funding made by the Trustees in November 2005 was effectively rejected.

That submission, which was entitled Funding Long Term Survival, was seen first by your immediate predecessor, Caroline Flint. It set out detailed, first hand evidence of what was needed in the fundamentally changed circumstances that victims who have survived so long, against all original expectations, may well now have a near normal life span but with the near certain threat of ever-declining health.

It appears to the Trustees that the grounds on which the submission was effectively rejected by the Department in July last year amounted in reality to the recent, well

publicised financial difficulties of the NHS. The Trustees' position is that it is simply unacceptable that our beneficiaries, whose lives have been shattered, and will continue to be blighted, by what has been described as "the worst ever treatment disaster in the history of the NHS", should be further disadvantaged by financial stringency within the NHS.

You will be aware that much has been made by Ministers in more recent statements of the great improvements that have been made in the financial position of the NHS. As I have indicated, the Trustees believe it is fundamentally wrong that, in the unique circumstances of their beneficiaries, the inadequate financial state of one part of Government should be used to justify the inadequate fulfilment of the commitment of the Government on behalf of the community as a whole.

Even so, it is very much to be hoped that, when the Trustees return to the Department, as they intend to do shortly, with a fully considered and fully evidenced re-statement of our beneficiaries' needs, reference will not again be made to the financial difficulties of the Department: rather that the Government will respond not just with more expressions of sympathy and regret but with the real and substantive fulfilment of all the commitments eviously expressed to provide the funds necessary to meet the needs of the victims and their families.

The Trust has always enjoyed a robust relationship with your officials and sought to work in partnership with them. However, their undoubted goodwill cannot by itself enable the Trustees to meet the needs of our beneficiaries to the full extent we have assessed to be necessary. What is required is such a renewal of the political commitment to the objectives of the Trust as will release the increased funding we need to achieve them.

I would welcome the opportunity to meet you and discuss these issues with you when you have been able to settle in to your new office and your new responsibilities for public health protection.

May I wish you every success in discharging those responsibilities.

Christopher FitzGerald Chairman