

Cabinet Secretary for Health and Wellbeing
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David Stewart
Convener
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The Scottish Parliament
EDINBURGH
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30 January 2013

Dear David

Consideration of New Petition PE1462

I wanted to provide you with the updated position in relation to Petition PE1462 which calls on the Scottish Parliament to urge the Scottish Government to make additional funding available for the immediate prescription of ivacaftor (Kalydeco) whilst awaiting published advice by the national new medicines appraisal body, the Scottish Medicines Consortium (SMC). I understand this was considered at the Public Petitions Committee meeting on 22 January 2013.

You will be aware that the SMC published advice on Monday 14 January 2013 to confirm that ivacaftor was not recommended for use within the NHS in Scotland.

I met with representatives from the Ivacaftor Patient Interest Group and the Cystic Fibrosis Trust on Thursday 17 January 2013 to discuss their concerns about the SMC's advice. You will be aware that I committed to fund the cost of ivacaftor for those patients suffering from cystic fibrosis who have not had a lung transplant and who have the G551D gene through the Rare Conditions Medicines Fund (RCMF). This is based on specialist clinical advice received that the pre-transplant group of patients would still carry the G551D gene mutation in their lungs and are therefore those most likely to benefit from ivacaftor as they could anticipate increased lung function and life expectancy.

NHS Boards have been advised of interim arrangements to progress such requests for ivacaftor for those patients described above pending the outcome of the New Medicines Review.

I am copying this letter to Duncan McNeil MSP, Convener of the Health and Sport Committee.

ALEX NEIL