



Department of Health sets out plans on Cystic Fibrosis drugs

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Orkambi campaigner Liam McHugh and Eleanor McHugh with Chief Pharmaceutical Officer Cathy Harrison, Permanent Secretary Richard Pengelly and Orkambi campaigners Jen Banks and Dermot Maguire.

The announcement follows the pricing agreement reached last week between NHS England and Vertex Pharmaceuticals, manufacturer of the drugs. This agreement stipulates that Vertex Pharmaceuticals must offer an equivalent pricing agreement for Northern Ireland and Wales.

Department of Health Permanent Secretary Richard Pengelly said: “The Department is delighted to be able to confirm its plans.

“This has been a very difficult and sensitive process. For patients with Cystic Fibrosis and their families, it has been a long and frustrating road.

“In the NHS England agreement there is a commitment that Vertex must make the drugs available to Northern Ireland patients on equivalent terms.

“That removes any feasible impediment to a localised agreement with the company. Discussions are being commenced with Vertex Pharmaceuticals and subject to that localised agreement being formally signed off, we will be able to start commissioning the drugs as a matter of urgency.”

Mr Pengelly thanked all those who had made representations to the Department on securing availability of the drugs. He paid tribute to the campaigning families who had made their case to him and colleagues.

He invited Orkambi campaigners Liam McHugh and Jen Banks to Stormont today to brief them on the situation.

The Permanent Secretary praised Departmental officials for their work on the issue.

“I also want to place on record my thanks to colleagues in England for working closely with us and getting this agreement in place,” he said.

He added: “Departmental policy, established by Ministers – is to follow

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re added. Departmental policy - established by ministers - is to follow NICE decisions on the commissioning of new drugs. NICE is supporting the agreement announced last week.

“Commissioning Orkambi, Symkevi and Kalydeco this year and in future years will therefore be in line with existing policy.

“It is no secret that the health budget in Northern Ireland is under severe pressure, with many competing demands being made for funding. As I have made clear, we cannot do everything we are being asked to do.

“In this case, we have benefitted from well-established arrangements on drug price appraisal and negotiation. I believe these processes have ultimately served us well, with a sustainable agreement that is good news for patients and taxpayers.”

Notes to editors:

1. In [his letter last week](#)  to the House of Commons Health and Social Care Committee, NHS Chief Executive Simon Stevens announced the agreement with Vertex, adding: “Wales and Northern Ireland have stood alongside NHS England throughout these extended discussions. We have therefore inserted into the legal agreement that NHS England has negotiated, a requirement that the company must make equivalent terms available to the NHS in Wales and Northern Ireland, should those jurisdictions wish to benefit from them.
2. For media enquiries please contact the Department of Health Press Office on 028 9052 0575 or email pressoffice@health-ni.gov.uk . For out of hours please contact the Duty Press Officer on 028 9037 8110.
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