Statement from North of England SCG on behalf of the four Specialised Commissioning Groups in England

Ivacaftor (brand name Kalydeco) for cystic fibrosis

The four Specialised Commissioning Groups (SCGs) in England have today (Wednesday 19 December) confirmed that ivacaftor will be funded by the NHS in England for all patients aged 6 years and over with cystic fibrosis and the G551D gene mutation.

The announcement follows several weeks of reviewing all the available evidence on clinical effectiveness and cost-effectiveness by the Clinical Priorities Advisory Group (CPAG) specifically established to consider this new treatment.

Cathy Edwards, Director of Specialised Commissioning in the North of England SCG and lead for this project said:

“CPAG was established in September 2012 to provide the four SCGs in England with a single source of national advice on the clinical and cost effectiveness of ivacaftor. Each Board of the four Specialised Commissioning Groups (SCGs) in England met during December 2012 to consider the recommendations put forward by CPAG.”

“Following these meetings, we can confirm that, from 1 January 2013, ivacaftor will be made available to NHS patients aged 6 years and over with the G551D gene mutation in England as set out in the licensed indication.”

The lead clinician in each of the cystic fibrosis specialist centres in England will be informed this week of the decision to fund ivacaftor. Cystic Fibrosis services will then start making arrangements for eligible patients.

Cathy added:

“This has been a thorough and inclusive process and we would like to thank the clinical expert members of the CPAG, the Cystic Fibrosis Trust and Vertex Pharmaceuticals for their hard work, cooperation and commitment which has enabled us to reach a final decision on making ivacaftor available to patients.”

Ends
Notes to editors

- There has been a rigorous process of assessment of the clinical and economic effectiveness of ivacaftor by the CPAG, which has made its recommendation based on a robust clinical and economic evaluation (Health Technology Appraisal) carried out by the NHS Institute for Health Research and a report from the national Cystic Fibrosis Clinical Reference Group, which is made up of expert clinicians, patient representatives, and representatives from the Cystic Fibrosis Trust and NHS commissioners.

- Cystic Fibrosis Centre Directors and commissioners will be provided with a suite of documents including policy and guidance documents, in order for them to implement this decision from 1 January 2013.


- The Yorkshire and the Humber office of the North of England Specialised Commissioning Group is the national commissioning lead for cystic fibrosis and works on behalf of the four Specialised Commissioning Groups in England.

- The Yorkshire and the Humber office of the North of England Specialised Commissioning Group commissioned a Health Technology Assessment of ivacaftor to provide a robust clinical and economic evaluation of the treatment. The final report was received in August 2012.

- The role of the Clinical Priorities Advisory Group (CPAG) was to advise the four SCGs on the clinical and cost effectiveness of ivacaftor.

- The CPAG adopted the decision making framework previously used by the Advisory Group for National Specialised Services (AGNSS) for the national commissioning of highly specialised services to ensure a fair and consistent approach. Further information on the AGNSS decision making framework can be found here.

- Two meetings of the CPAG took place on 25 September 2012 and 22 October 2012, which focused on the clinical and cost effectiveness of ivacaftor, respectively.

- Representatives of the Cystic Fibrosis Trust and the manufacturers of ivacaftor (Vertex Pharmaceuticals) were observers at the two meetings of the CPAG.

- The minutes of the CPAG have been published on the North of England SCG (Yorkshire and the Humber Office) website (www.yhscg.nhs.uk) and the CF Trust website (www.cftrust.org.uk)

- The membership of the national Cystic Fibrosis Clinical Reference Group includes clinicians, patient representatives, representatives from the Cystic Fibrosis Trust and NHS commissioners.

- Ivaacaftor is a new type of medicine for cystic fibrosis that is only licensed for the treatment of patients aged 6 years and older with cystic fibrosis who have a G551D mutation. There are about 270 people in England who are currently eligible to receive it.