Lumacaftor–ivacaftor for treating cystic fibrosis homozygous for the F508del mutation

Information for the public
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What have NICE and NHS England said?

November 2019: Although NICE does not recommend lumacaftor–ivacaftor (Orkambi) for treating cystic fibrosis in people 12 years and older who are homozygous for the F508del mutation, NHS England has said that it is now available on the NHS for treating cystic fibrosis.

The condition and the treatment

Cystic fibrosis is an inherited disease that affects the lungs by clogging them with thick and sticky mucus. This causes coughing, shortness of breath and increases the risk of lung infections.

People who are homozygous for the F508del mutation have 2 copies of a faulty gene,

which results in cystic fibrosis.

Lumacaftor–ivacaftor helps to treat the cause of cystic fibrosis.

The NHS website may be a good place to find out more.

These organisations can give you advice and support:

- Cystic Fibrosis Trust, 0300 373 1000
- British Lung Foundation, 03000 030 555
- Contact a Family, 0808 808 3555

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

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Accreditation