

29 September 2021

Funding and costs of Kalydeco (Ivacaftor) Trial: NCT00909532 (Cystic Fibrosis)

Note that this request pertains specifically to “Belfast City Hospital”.

Under the Freedom of Information Act 2000, please provide me with all of the following:

- 1) Details of all parties that have contributed funding to the trust in relation to the Kalydeco (Ivacaftor) trial NCT00909532 being conducted at your site/s.**
- 2) A list of all sites within your trust that Kalydeco (Ivacaftor) trials have been conducted at.**
- 3) Numbers of Kalydeco (Ivacaftor) trial participants at each trial location, for the NCT00909532 trial.**
- 4) Number of staff involved in conducting the trial at each trial location, listing their roles, for the trial, NCT00909532**
- 5) What costs were incurred by the trust in order to conduct the Kalydeco (Ivacaftor) trial, NCT00909532? If a document does not state the total budget or cost of a trial, but lists the actual or expected costs of any aspect of the trial, it would also be subject to this request. If a document states the yearly budget for a clinical trial, that would be pertinent as well. This includes per-patient costs in conducting the trial. The simplest response would be to provide the cost in GBP of either the budget for the trials or the actual outlays, and both if that is possible.**
- 6) A breakdown of any funding received from internal and external sources in order to conduct the Kalydeco (Ivacaftor) trial, NCT00909532. Please break funding down into i) funding from public (governmental) bodies, ii) private entities, and iii) philanthropies/charitable bodies. Please include the full name of the funding body. Please specify amounts in GBP. (Please provide this as an excel spreadsheet)**
- 7) A record of all expenses incurred in conducting the Kalydeco (Ivacaftor) trial, NCT00909532.**

Belfast Trust do not hold this information.

You should direct your FOI to Professor Stuart Elborn, who previously worked for the Belfast Trust Cystic Fibrosis team and reportedly led on this study. Contact details below from QUB website:

Professor Stuart Elborn, Pro-Vice Chancellor for Medicine, Health and Life Sciences
Queen's University, Belfast, 90 Lisburn Road, Belfast, BT9 6AG