

2024.09.10

**2.1 Deputy G.P. Southern of St. Helier Central of the Minister for Health and Social Services regarding use of the drug Kaftrio in the treatment of a specific mutation of cystic fibrosis (OQ 154/2024):**

Further to the recent use of the drug Kaftrio in the treatment of a specific mutation of cystic fibrosis, will the Minister advise what mechanisms, if any, are in place to provide this treatment to other patients suffering from this long-term condition?

**Deputy T.J.A. Binet of St. Saviour (The Minister for Health and Social Services):**

There is a mechanism in place that can facilitate the provision of treatment for the specific condition mentioned by the Deputy. It is the same one that was deployed in the case referred to in this question. Given that the treatment involves a very high-cost drug, the patient's clinician is required to submit an independent patient funding request, or I.P.F.R., to the I.P.F.R. panel. In the event that that does not prove successful, the clinician can then refer it to a separate I.P.F.R. appeal panel. This was the route taken recently for the first successful applicants, and I remain grateful to the Deputy for raising the issue in the Assembly, given that it gave rise to the successful appeal. Through this process, which applies to all such drugs, it is not unusual for a trial period to be approved so that the effectiveness of the treatment can be assessed and, in the event of it proving successful, ongoing treatment can then be sanctioned. Finally, I am happy to inform the Assembly that in this initial case the treatment has worked well and the ongoing treatment has been approved. In addition to that, 2 further patients have now been approved for a 3-month trial period. I think it is safe to assume that the application mechanism we have in place is working appropriately.

**2.1.1 Deputy G.P. Southern:**

Just in general, to what extent do the U.K. (United Kingdom) N.I.C.E. (National Institute for Health and Care Excellence) guidelines apply in Jersey and how independent is Jersey in order to assess such treatments?

**Deputy T.J.A. Binet:**

I am aware that Deputy Southern keeps a very close eye on this and, as I have stated, I am grateful to him for doing so. There has been some correspondence in the middle of August relating to this. It is not a matter I have had a chance to address but I have got an appointment with the deputy medical director on Monday to go into that in more detail. So, I am very happy to keep the Deputy informed as things progress.