

2024.03.19.

5.1 Deputy G.P. Southern of St. Helier Central of the Minister for Health and Social Services regarding the use of Kaftrio to treat cystic fibrosis patients (OQ.44/2024)

It is a pleasure to be first up. Given the Minister's response to Written Question 30/2024 and recent research findings, will he agree as a matter of urgency to review, in consultation with appropriate officers, the decision of 13th December 2023, made by the Medicines Optimisation Committee, on the use of Kaftrio to treat cystic fibrosis patients carrying the specific gene mutation N1303K for a trial period of 3 months as an exception to N.I.C.E. (National Institute for Health and Care Excellence guidelines)?

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

I would like to thank the Deputy for bringing this to my attention. I have to say that I maintain my position in feeling that it is not appropriate for me to intervene directly in clinical matters. However, in light of the evidence provided, I have already referred the matter back, along with the 6 connections that the Deputy kindly provided, to the Medicines Optimisation Committee and asked them to take another serious look at it.

5.1.1 Deputy G.P. Southern:

Does the Minister have any idea of the timescale in which he might be able to produce a judgment from his committee, and indeed from the department, as to the urgent nature of treatment for C.F. (cystic fibrosis) patients in the department?

Deputy T. Binet:

I have to confess, I did not think to set a timeline for this, but I would hope, given the nature of it, that the committee would take the occasion to look at it at their next meeting.

5.1.2 Deputy T.A. Coles of St. Helier South :

Does the Minister know or can the Minister confirm the number of Islanders that suffer with cystic fibrosis?

Deputy T. Binet:

I am afraid I cannot. This was only brought to my attention at the end of last week, but I am certainly happy to look into that as well.

5.1.3 Deputy G.P. Southern:

Can I ask the Minister to study what has already been found?

[9:45]

I have a letter from the committee saying that should new studies come to light they will research and re-examine their judgment on this matter. Could he ensure, to the best of his ability, that this is brought back to his department in short order?

Deputy T. Binet:

Yes, I am very happy to confirm that I will do that.