



5 August 2025

Deputy Conor D. McGuinness, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 40604/25

To ask the Minister for Health the amount of funding given to each county as part of the rare diseases fund in each of the years 2014 to 2024 and to date in 2025, in tabular form; and if she will make a statement on the matter

Dear Deputy McGuinness,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Advisor and Group Lead for Children and Young People (NCAGL C&YP) on your question and have been informed that the following outlines the position.

Funding for healthcare and new service developments are commissioned and delivered at national and regional levels, rather than on a county-by-county basis. As such, records of funding allocated specifically by county are not available.

The National Rare Disease Office (NRDO) was established by the HSE in 2015 and serves as a national rare disease coordination hub, supporting people living with rare disease by improving access and quality of service nationally.

Funding was allocated for new service developments for rare diseases in 2025 (HSE National Service Plan 2025: Page 88)¹, to enhance care for people living with rare diseases, by supporting improved care coordination, strengthening data management at European Reference Network (ERN) leading sites and supporting the implementation of the forthcoming National Rare Disease Strategy 2025–2030.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely

Anne Horgan
General Manager

References

1. https://about.hse.ie/api/v2/download-file/file_based_publications/hSE-National-Service-Plan-2025.pdf