

Patient representatives welcome the announcement of €5 million in additional funding for rare diseases

8 November 2024

Patient advocacy members of the National Rare Disease Steering Group, have welcomed the announcement of Minister for Health, Stephen Donnelly, TD that an additional €5 million in recurring funding has been allocated for rare diseases in 2025. This brings the total of new funding for rare diseases to €6.5 million in 2025 which will rise to €8 million in 2026. This funding will support implementation starting in 2025 of the soon to be published National Rare Disease Strategy for Ireland.

Around one in 17 people live with a rare disease, so while diseases are individually rare, they cumulatively affect a substantial proportion of the Irish population, estimated at 300,000 people. The impacts on people living with rare diseases and their families are wide-ranging. Rare diseases are chronic, progressive, degenerative and often life-threatening. They carry with them significant levels of morbidity and disability, including cognitive, developmental, intellectual, mental, physical and sensory challenges, and are a significant contributor to infant and child mortality and reduced life expectancy.

The collective advocacy of people living with rare diseases has grown in recent years, culminating in this significant investment by the Government. The Strategy is being developed with the voice of people living with rare diseases at the heart of deliberations through four representatives on the Steering Group - Gillian Stafford, Alan Finglas, Vicky McGrath and Derick Mitchell. In addition, a 100-strong Rare Disease Patient Forum, supported by the office of the Chief Medical Officer in the Department of Health, continues to provide input from the rare disease community into the strategy and will play a role in its implementation beyond 2024.

This new investment will allow the health service to deliver changes demanded by people living with rare diseases and their care givers to alleviate the burden of a rare disease diagnosis. Expanded patient partnerships, improved care coordination, and a strengthened National Office for Rare Diseases will ensure that this investment delivers change on the ground for those most affected by rare diseases.

Gillian Stafford, living with rare diseases said: “It is gratifying to see this investment coming at this time as we complete development of the Strategy. People living with rare diseases have been heard and this investment is testament to all of our hard work. We can begin to hope now for integrated coordinated care for all of us.”

Alan Finglas, father of a child (Dylan) that is living with a neuro degenerative rare disease added: “I am delighted to hear about this investment. It is a long time coming. I look forward to seeing these funds being used wisely to improve healthcare, quality of life, and for the potential for a future that is a little brighter for patients that are affected by rare disease and their families that love them dearly.”

Welcoming the announcement, Vicky McGrath, CEO RDI said “People living with rare diseases experience delays with diagnosis, limited and disjointed access to specialist expertise and treatments and inadequate care in the community. We welcome this investment as the first step in delivering equitable access to healthcare for people living with rare diseases in Ireland, as envisioned under Sláintecare.”

Commenting on the investment, Derick Mitchell, CEO IPPOSI said “this recurrent funding dedicated to rare diseases is a first for Ireland and is very welcome. It reflects the intention of all involved to improve and scale up the coordination of services, research, care and partnerships specifically for rare diseases, in line with the vision and ambition of the new strategy.

Dept. of Health Announcement: <https://www.gov.ie/en/press-release/4cfec-minister-for-health-announces-additional-5-million-funding-for-rare-diseases/>

About RDI

Rare Diseases Ireland (RDI) is the national alliance for rare disease patient organisations in Ireland, working across all rare diseases to improve the lives of the estimated 300,000 people living with rare diseases in Ireland.

Our vision is a country where all people living with rare diseases live longer and better lives, reaching their full potential, and are included in a society that leaves no one behind. We want equity for people living with rare diseases in Ireland – equitable access to diagnosis, treatment, health and social care and opportunity.

www.rdi.ie

About IPPOSI

The Irish Platform for Patients’ Organisations, Science and Industry (IPPOSI) is a unique, patient-led partnership in Ireland and internationally. The platform brings together patient groups, scientists, clinicians, industry professionals, and other key decision-makers to build consensus on issues relevant to all involved in delivering treatments and innovations to people with unmet medical needs.

The IPPOSI vision is that the patient voice is at the centre of all health policy, care, research and innovation in Ireland. To that end IPPOSI develops and implements initiatives such as workshops, education programmes, citizen juries and conferences on policy, legislation, regulation related to health innovation in Ireland. More about our work can be found at www.ipposi.ie.