

Rare Disease Patient Representatives Welcome the Development of a New Rare Disease Strategy for Ireland

7 December, 2023 – The Irish Platform for Patient Organisations, Science and Industry (IPPOSI) and Rare Diseases Ireland (RDI) welcome the announcement from the Minister for Health Stephen Donnelly on the establishment of the National Rare Disease Steering Group, tasked with developing a new 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.

IPPOSI CEO Dr. Derick Mitchell and RDI CEO Vicky McGrath have agreed to co-chair a Rare Disease Patient Forum, supported by the office of the Chief Medical Officer in the Department of Health. With a patient-centred approach, this forum will aim to gather and collate input from the rare disease community, particularly focusing on ‘the lived experience’ of patients and families to inform the development of the plan.

Welcoming the initiative, Derick Mitchell said “The delivery of this new strategy, despite the challenges of the current environment, shows the commitment of the government to make meaningful progress. Engaging delivery partners and patient groups is essential in crafting and executing a comprehensive strategy for rare diseases in Ireland. As we approach Universal Health Coverage Day on 12 December, it is imperative that we recognise that true universality in health and social care extends to the 300,000 people living with a rare disease in Ireland. In developing this new plan, we want to work collaboratively to ensure that no one is left behind as we move towards accessible, inclusive, and coordinated care for all.”

Speaking ahead of the inaugural meeting on 7 December, Vicky McGrath 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 the focus on addressing gaps in healthcare services and integration of care, including that provided by the expert European Reference Networks, across the Irish healthcare system for people affected by rare diseases. We will work to ensure that this strategy delivers for all people living with rare diseases, by ensuring earlier, faster and more accurate diagnosis, integrated



national and European care pathways and improved person-centred and lifelong holistic treatment and care.

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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.

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.