

**Rare Diseases Ireland Statement on
'cocooning' measures to protect against COVID-19**

April 1st 2020 – Dublin, Ireland. Rare Diseases Ireland (RDI) welcomes the new public health measures announced by the Irish Government on March 27th/28th. These measures are designed to halt the spread of coronavirus in our communities and to protect extremely medically vulnerable people from COVID-19.

Extremely medically vulnerable people include those with rare diseases as outlined in the advice available from the Health Service Executive (HSE)/Health Protection Surveillance Centre (HPSC). Such people are advised to minimise interactions with others and implement 'cocooning' measures as detailed by the HSE/HPSC.

The current coronavirus pandemic has placed enormous strains on the capacity of the health services in Ireland. RDI welcomes the announcement that capacity is being added to the existing services by way of a public-private partnership with the private hospitals in the country. We hope that this additional capacity will go a considerable distance towards providing the resources necessary to address the needs of those affected by the pandemic while also providing safe environments to provide for the ongoing complex care needs of the rare disease patient community.

RDI strongly advises all patients with rare diseases which put them at very high risk of severe illness from coronavirus to rigorously follow cocooning measures in order to keep themselves safe. If patients have a scheduled hospital or other medical appointment during the cocooning period, they should talk to their GP or specialist to ensure they continue to receive the care they need. Together they can determine what medical assistance can be assessed/provided remotely and what appointments are absolutely essential to attend in person. If a patient has urgent care needs, they should talk to their GP or specialist in the first instance if possible or, if an emergency, call 112 or 999. A&E services remain open but should be avoided if there is any suspicion of coronavirus infection. .

About Rare Diseases Ireland (RDI)

RDI is the national alliance for voluntary groups representing people affected by or at risk of developing a rare disease. There are an estimated 300,000 people living in Ireland with a rare disease. RDI is committed to the identification, treatment, and cure of rare diseases and care for those living with a rare disease.

For further information contact Vicky McGrath, CEO vicky.mcgrath@rdi.ie