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Dear Members, Partners & Friends,

We at Rare Diseases Ireland would like to express support for those individuals and families affected by COVID-19. We stand in solidarity with everyone affected by the pandemic in Ireland, across Europe and around the world. Our thoughts are with all vulnerable populations, people with underlying health conditions and weak immune systems, the elderly, and every other affected community. We are particularly conscious of the stress the pandemic is causing to people living with a rare disease, their families and their carers.

Protective measures and containment are crucial to halt the spread of the virus and we are fully supportive of their implementation. However these measures may also make it more difficult for you to go to hospital appointments or get medicines at the pharmacy. The measures may disrupt the organisation of the specialised healthcare services you need or generate medicine shortages. The HSE are aware of these challenges and concerns and are working to move appointments on-line (where possible) and provide safe environments where face-to-face appointments are required. They are also working to ensure continuity of supply of medicines. We are supportive of these moves and ask for everyone to be patient as these measures are put in place.

We are happy to be able to tell you that the HSE's National Rare Disease Office (NRDO) information line continues to operate with its normal hours, and can address some of your queries at this time. The [NRDO](#) may be contacted by email at [rare.diseases@mater.ie](mailto:rare.diseases@mater.ie) and by phone at (01) 854 5065. We are advised that genetic services have been put on hold for all except those requiring prenatal testing. The usual referral pathways for prenatal genetic services via your GP and/or obstetrician remain in place.

Social distancing measures may also present challenges for patient organisations both for delivery of services and, particularly, with respect fund-raising initiatives and financial sustainability. Please remember to support your patient organisation at this particularly difficult time. Many organisations are moving their fund-raising efforts on-line and they need the help of the wider community to continue their support and spread the word.



We will continue to closely follow developments with COVID-19, particularly those that have specific implications for the rare disease community (such as disruption in delivery of services, supply of medicines and provision of medical devices) and liaise with patient organisations in order to identify issues which may require our support.

The commitment of healthcare professionals, carers and pharmacists is an inspiration to all as they bravely fight the virus on the frontline whilst still providing care and support for their other patients with chronic conditions. To prevent the spread of the virus and in support of these professionals, we encourage you to follow the guidelines given by the HSE for the [general population](#) and for [at-risk groups](#). Likewise patient organisations are committed to continue providing support and services where and however they can. Many organisations have developed resources to support the community. Some of these are available via our [website](#).

In the face of isolation and uncertainty, minding our mental health will be one of the immediate challenges that we all face. The HSE has some simple and sound [advice](#) to help to minimise this. Now is the time to pick up the phone, make a video call and stay in touch with each other. Please don't hesitate to contact Rare Diseases Ireland by email at [advocacy@rdi.ie](mailto:advocacy@rdi.ie) if we can help you. Mutual support is key.

The experience of rare diseases is one of resilience and agility. The rare disease community has emerged with, and built its strength on new information technologies, the internet and digital networking. We lean on the solidarity of this community, which has existed for decades across diseases, communities and borders, to come together virtually to comfort each other and move forward with our work.

As we continue to adapt our working methods and activities for the weeks and months ahead, please follow RDI on Twitter (@RareDiseasesIE) and check out our [website](#) where we will add information and resources as they become available. Where possible we will move meetings on line and reschedule events where required. The determination of the entire rare disease community will be key and we thank everyone in the rare disease community and wider society for their dedication and consideration in this unprecedented situation.

Sincerely,

A handwritten signature in black ink, appearing to read "Vicky McKeown", is written over a solid black horizontal line.

CEO  
Rare Diseases Ireland