

“I’m afraid my son will deteriorate without services”
**People Living with Rare Diseases Increasingly Concerned
for Health and Well-being**

**Rare Diseases Ireland Calls on Government to
Ensure Healthcare Services are Resumed for People
with Rare Diseases During Pandemic**

**- Research by Rare Diseases Ireland
highlights detrimental “knock-on” impact of coronavirus on rare disease community -**

Date of issue: Dublin, May 21, 2020

Rare Diseases Ireland has today called on the Government to ensure the provision of healthcare services for people with rare diseases, noting: “in our collective efforts to combat one disease, COVID-19, it is important that other diseases are not left behind”.

Almost three quarters of respondents (73 per cent) to a Rare Diseases Ireland research report among the rare disease community are concerned that their condition, or that of their loved ones, may deteriorate due to the impact of COVID-19 on their treatment and care.

More than half (53 per cent) have had scheduled medical appointments cancelled, while a quarter (26 per cent) indicated that they have encountered difficulty accessing medicines and medical supplies. Against this backdrop, it is perhaps unsurprising that almost two-thirds (62 per cent) believe that COVID-19 is having a negative impact on their mental health.

The report, *Living with a Rare Disease in Ireland during the COVID-19 Pandemic*, has highlighted how COVID-19 is hindering access to routine treatment and care for people with rare diseases, and is having a detrimental effect on their health and well-being.

The research provides a snapshot into life today for people with rare diseases, with responses from 176 people living with a rare condition, their family members and their carers, from across the island of Ireland. It was undertaken by Rare Diseases Ireland, the national alliance for rare disease voluntary groups, in the two-week period leading up to May 6.

Key Research Highlights

- **Impact on rare diseases:** Three quarters (73 per cent) of respondents indicated that they were concerned about their own, or their loved one’s, rare disease. They are concerned about how the condition is deteriorating without access to the usual healthcare, and how an already complex health situation may be negatively impacted if

infected with COVID-19. In such circumstances, they are worried how the rare condition may be perceived if ICU care is required. Three in five respondents (62 per cent) believe that COVID-19 is having a negative impact on their mental health.

- **Medical appointment cancellations:** more than half of respondents (53 per cent) responded that scheduled medical appointments have been cancelled. These included hospital appointments, such as diagnostic/monitoring procedures, surgical procedures and in-patient/out-patient therapies, as well as the cancellation of appointments for physiotherapy, occupational therapy, and speech and language therapy.
- **Accessing medicines:** one in four respondents (26 per cent) noted that there were difficulties accessing medicines and medical supplies needed for the condition.
- **Delaying seeking medical help:** three in ten (31 per cent) respondents have avoided seeking care for complications related to the condition because of concerns over exposure to COVID-19 and confusion over the availability of the usual hospital consultant to provide care.

Leave No One Behind

According to Vicky McGrath, CEO of Rare Diseases Ireland, the Government needs to take into account the full range of people's medical needs during this pandemic, including those with rare diseases:

“Since COVID-19 arrived in Ireland, we have witnessed huge restrictions on hospitals for everything except COVID-19 and emergency care. The fact that rare disease care is routinely provided by hospital-based consultants within the hospital setting, has had particularly negative consequences for the care of rare disease patients during this pandemic.

“Many respondents have expressed frustration and disappointment with the lack of communication from their health care providers. They have been left to cope for themselves and are struggling to know how best to manage. For those who previously accessed private healthcare, they are now unsure as to who is managing their care, and are concerned that they will go to the bottom of public waiting lists.

“More than half of those who responded to our research study indicated that scheduled medical appointments have been cancelled and I have no doubt that the experiences relayed are reflective of the wider rare disease community. It is extremely worrying for people and the cancellation of such a large number of appointments will inevitably lead to spiralling waiting lists and extensive delays.

“Many people with rare conditions spend years pursuing a diagnosis in the hope of therapeutic relief, so it is particularly frustrating when we hear of empty hospital beds and under-utilised resources. In our collective efforts to combat one disease, COVID-19, it is important that other diseases are not left behind.

“Steps taken by the health authorities in our hospitals and community healthcare facilities at the outset of this pandemic were widely accepted and understood by the rare disease community. However, we are now calling for all hospital and community healthcare services to be reopened for all patients in a safe manner. In addition, urgent measures need to be put in place to ensure that such severe service curtailments do not have to be applied in the event of any possible future resurgence of the virus, and that treatment and care for rare diseases can co-exist alongside that for COVID-19.”

Among the comments from the research respondents were:

- “I have a terminal rare condition and am not able to see family and friends as time runs out”
- “I am scared if they have too many persons in intensive care, would they make the decision not to treat me?”
- “(We) need priority access to vaccines when available for individuals with rare conditions”
- “No advice received from consultant or hospital team... unlike NHS patients who received a letter detailing cocooning”
- “Prescription has to be written by consultant, who I can’t get to see at present”
- “(Unable to) access the wider range of low-protein foods that a larger supermarket would have” (for a particular condition, due to 5KM restriction and Garda checkpoints)
- “My vision has changed but I have not checked it out”
- “I had bad pains in my lower right abdomen but was afraid to go to A&E”
- “I am visually impaired and will have to re-learn geography after cocooning”
- “Who will come to my house if my parents become ill? I need 24/7 constant care”
- “I’m afraid my son will deteriorate without services”

Thousands of Rare Diseases

There are an estimated 6-8,000 rare diseases. They are chronic, progressive, degenerative, often life-threatening, and associated with multiple impairments including cognitive, developmental, intellectual, mental, physical and sensory.

Around six per cent of the population in Ireland is estimated to have a rare disease, or approximately 300,000 people. At least four per cent of children born in Ireland in the year 2000 were diagnosed with a rare disease by age 17.

For more information on rare diseases in Ireland, visit www.rdi.ie



ENDS

Issued on behalf of Rare Diseases Ireland by: Don Delaney, tel. 01 9108987 / 087 7933249 or email

don@d2communications.ie

About Rare Diseases Ireland

Rare Diseases Ireland (RDI) is the national alliance for voluntary groups representing people affected by, or at risk of developing, a rare condition. RDI is committed to the identification, treatment, and cure of rare diseases and care for those living with a rare condition.