

## 9 in 10 people living with a rare disease experiencing interruption in care because of COVID-19

### Survey shows detrimental impact of coronavirus on rare disease community

4 May 2020, Paris - EURORDIS-Rare Diseases Europe today announces preliminary global results from the first multi-country survey on how COVID-19 is affecting people living with a rare disease, finding that the pandemic greatly hinders access to care.

The COVID-19 pandemic has exacerbated the many challenges people living with a rare disease already face and has created extra risks in their daily lives, with collateral consequences.

- Since the beginning of the COVID-19 pandemic **9 in 10** are disease patients have experienced interruptions of the care they receive for their rare disease:
  - **6 in 10** of those who declared an interruption of care related to the COVID-19 pandemic said this is detrimental to their health or the health of the person they care for.
  - **3 in 10** perceive that these interruptions of care could definitely (**1 in 10**) or probably (**2 in 10**) be life-threatening.
  - **More than a half** of those who need surgery or transplant have seen these interventions cancelled or postponed.
  - **8 in 10** have seen their appointments for rehabilitation therapies such as speech and physical therapies (sometimes the only therapies accessible when treatments are not available) postponed or cancelled.
- Patients who usually receive care in hospitals are experiencing specific difficulties, with almost **3 in 10** reporting that the hospital or unit that normally provides care for their rare disease is closed.
- **1 in 2** have participated in online consultations or another form of telemedicine since the start of the pandemic. This is new for **2 in 10** patients. Almost **9 in 10** of those who have experienced this type of consultation are happy with the experience and that it has been very or fairly helpful.

**5,000+ rare disease patients and their family members from all EU countries and beyond representing 993 diseases responded to the survey** carried out via the Rare Barometer Programme. These results are based on survey responses submitted between 18 and 28 April 2020. These are preliminary figures and the survey continues throughout the duration of the crisis. Rare diseases are often chronic and life-threatening.

**Sandra Courbier, Social Research Director at EURORDIS**, commented "It is clear the COVID-19 pandemic has a collateral impact on the health and quality of life of the 30 million people living with a rare disease in Europe, and indeed around the world. For years, EURORDIS has been collecting data on the experiences of people of living with a rare disease that demonstrates the immense difficulties they already have in accessing care, finding the right

specialist and appropriate therapies. By creating new barriers, the current pandemic is worsening this already difficult situation. We are seeing cases where this triggers a strong feeling of anxiety among families. We call on policy makers and public officials to remember how vulnerable our community is and to make efforts, whenever possible in the post-confinement period; to be mindful of and protect people living with a rare disease”.

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## Additional key findings of the survey:

### Rare disease patients are experiencing interruptions of the care they receive for their rare disease

Since the beginning of the COVID-19 pandemic, and for those who need the following aspects of the care provided by healthcare professionals:

- Almost 6 in 10 do not have access to medical therapies at home or at the hospital anymore, such as infusions, chemotherapy and hormonal treatment.
- More than a half of those who need surgery or transplant saw their interventions cancelled or postponed.
- More than 6 in 10 do not have access to diagnosis tests such blood or cardiac tests and medical imaging - that are often crucial part of their daily care – anymore.
- Close to 7 in 10 have seen their appointments with the general practitioners or specialists who provide care for the rare disease cancelled.
- Almost 6 in 10 have seen their psychiatry follow-up interrupted.

**A female carer in Belgium** commented, “For now, we no longer have a follow up with nephrology specialists concerning the transplant. One meeting has been cancelled, the last blood test was in January even though there should be one done every 2 months. Psychological and psychiatric follow-ups for ADHD and anxiety have been cancelled because there are no longer any consultations at the hospital and the private care is too expensive for me. I have a hyperactive son in the house 24 hours a day.”

### Patients treated in hospitals are experiencing specific difficulties

For patients who receive follow-up care in hospitals, getting access to the care they usually receive is difficult because hospitals are obviously not in the same capacity to deliver this necessary care:

- Almost 3 in 10 report that the hospital or unit that provides care for their rare disease is closed.
- More than one in then declare that the necessary material needed for the rare disease care was missing because it is now used for patients affected by COVID-19.
- And finally, more than 3 in 10 are even explicitly told not to go to a hospital if they or the person they care for becomes unwell for other reasons than being affected by COVID-19.

The fear of catching COVID-19 is also a major obstacle to receiving the care they need in hospitals: half of those who receive follow-up care through hospitals did not go to the hospital because they were fearful themselves or the person they care for might catch COVID-19.

## These interruptions have a detrimental impact on their health

6 in 10 declare that interruptions of care related to the COVID-19 pandemic they are experiencing are detrimental to their health or the health of the person they care for and 7 in 10 to their well-being.

Interruptions of care that are mentioned above, in particular surgery or transplant, cancellation of medical therapies or diagnosis test are perceived as life-threatening for a significant share of patients. 3 in 10 of the respondents declare that such interruptions related to the COVID-19 pandemic definitely (10%) or are perceived as probably (22%) having a life-threatening impact on them or the person they care for.

## Respondents are praising the additional effort made by their healthcare professionals to provide care for their rare disease despite hurdles generated by the COVID-19 pandemic

**A female patient from the UK** stated, "I have had to go to hospital to go to clinics and to receive Rituximab. Staff have taken every possible measure to protect me. I know the staff and they have made every effort to help me".

## About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 900 rare disease patient organisations from 72 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.

By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

## About the Rare Barometer Programme

The [Rare Barometer Programme](#) is the EURORDIS survey initiative that brings together over 11,000 rare disease patients, family members and carers who share their experiences and opinions on the issues that matter to the rare disease community.

The Rare Barometer survey software enables high-quality, secure data collection and analysis. The Programme was created to systematically collect patients' opinions on transversal topics and introduce them into the policy and decision-making process, transforming patients' and families' opinions and experiences into figures and facts that can be shared with a wider public and policymakers.

## About rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date affecting an estimated 30 million people in Europe and 300 million worldwide.

72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

## Contacts

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