People living with a rare disease were severely impacted during first COVID-19 wave: 30 million people in Europe must not be forgotten once again

Survey shows 84% of people living with a rare disease experienced disruption of care

11 November 2020, Brussels – EURORDIS-Rare Diseases Europe publishes the final results of a multi-country survey highlighting the detrimental effect of the first wave of the global pandemic on 30 million people living with a rare disease in Europe, and calls for continued and reinforced efforts to protect this vulnerable population during the current second wave and beyond.

The COVID-19 pandemic has exacerbated many of the daily challenges of those living with a rare disease and has created extra risks in their everyday lives, according to a survey of almost 7000 respondents from across Europe.

As the region is faced with a second wave of COVID-19, EURORDIS-Rare Diseases Europe is calling on policy makers to ensure that the devastating impact of the pandemic does not become the new normal for people living with a rare disease. The results of the survey conducted during the first wave can meaningfully be extrapolated to the ongoing second wave and beyond.

Carried out between 18 April and 11 May 2020, the survey recorded the significant impact that the first wave of the COVID-19 pandemic was having on the treatment, care and living conditions of 7000 people living with a rare disease or caring for rare disease patients across Europe.

- **84% of European rare disease patients surveyed experienced some sort of disruption of their care due to the COVID-19 crisis.**
    - **64% of respondents said that they were concerned this would be detrimental to their health** or the health of the person they care for.
    - **3 in 10 respondents reported that this would probably (2 in 10) or definitely (1 in 10) be life-threatening.**

- **Among those who reported a disruption of care:**
    - **6 in 10 were unable to access diagnostic tests**
    - **6 in 10 were unable to receive therapies** such as chemotherapies or infusions
    - **6 in 10 saw their surgery or transplant postponed or cancelled.**

As rare diseases are often highly debilitating and life threatening, this wait for diagnostic tests or for medical interventions can result in a severe deterioration of symptoms.

In addition, these disruptions to care and the isolation experienced during lockdowns had a severe impact on the mental health of people living with a rare disease, with **almost 6 in 10 seeing their psychiatry follow-up interrupted** and **two thirds of respondents suffering from depression and/or a feeling of not being able to overcome their problems** since the beginning of the pandemic.

With healthcare systems once again strained under the pressure of COVID-19 and the reintroduction of lockdowns across Europe, it is imperative that measures are taken to mitigate such impact. We hope that plans towards a European Health Union, due to be announced by the European Commission today, will work to address the needs of people living with a rare disease during and after the pandemic.

EURORDIS wishes to highlight, among its detailed list of recommendations issued during the first wave of the pandemic:

- the need to safeguard the continuity of care and access to medical consultation for people living with a rare disease by directing funds and efforts towards healthcare systems to reinforce medical workforce and equipment;
- the adoption of concrete measures/ protocols warranted by the complex needs of rare disease patients in the provision of emergency healthcare;
- the need for minimum support service and personal assistance service for vulnerable populations, including people living with a rare disease;
- Encourage and facilitate practices like virtual consultations (telemedicine) or the administration of certain therapies in the home setting; and
- the importance of waiving rare diseases patients, and parents and caregivers of rare disease patients (adult or child) from requirements to return to school, university or the office if/when remote learning and working is possible - as exposure to the virus puts them and their loved ones at greater unnecessary risk and they play a key role within the support system of the patient.

The survey results also underline the need to move towards more resilient and shock-resistant healthcare systems that do not exacerbate the vulnerabilities of people living with a rare disease across Europe as seen during the first wave of the pandemic, but works to protect them.

> **Yann Le Cam,** Chief Executive Officer, EURORDIS-Rare Diseases Europe commented:
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> **"**People living with rare diseases in Europe have found themselves caught as collateral damage of the COVID-19 pandemic, facing interruptions to their care that could be life-threatening. The risk of exacerbating inequalities that already exist for these patients is very real.
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> **The second wave of COVID-19 across Europe has made it clear we will now be living with the pandemic for a long period. That means that governments and healthcare systems have to move away from a fire-fighting approach, and work towards building more sustainable and resilient healthcare systems that do not forget the needs of the most vulnerable in the cloud of COVID-19. We need sustainable healthcare systems that leave no one behind – including the 30 million people living with a rare disease in Europe."**

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Additional key findings from the survey

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About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 930 rare disease patient organisations from 73 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 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.