

Rare disease community raises alert over discrimination in critical care guidelines during COVID-19 pandemic

EURORDIS urges immediate action and proposes concrete solutions

31 March, Paris - EURORDIS-Rare Diseases Europe is alarmed by reports from member organisations and individuals that people living with a rare disease are being discriminated against in critical care guidelines* designed to steer emergency/ICU doctors in the prioritisation of patients during the COVID-19 pandemic (*documented in Germany, the Netherlands, Spain, UK and Switzerland, and based on non-documented reports from Belgium, France and Italy*).

We urge policy makers and authorities in Europe and around the world not to leave behind people living with severe chronic diseases, rare diseases or disabilities during this crisis, and to take action to protect these populations in line with the proposals listed below.

Terkel Andersen, President of the Board, EURORDIS, commented, "We praise the efforts of and sympathise deeply with all healthcare professionals currently fighting COVID-19 on the frontline. However, people living with a rare disease are amongst the most vulnerable groups in society. Their diseases are highly complex, often chronic and severely disabling conditions, which generate specific care needs. Their vulnerability is exacerbated during the current crisis. This is even more the case for people affected by rare immunodeficiency diseases or using immunosuppressants (including rare cancers and organ transplanted patients), rare pulmonary diseases like cystic fibrosis or HHT, and rare neuro-muscular diseases such as DMD and SMA."

EURORDIS anticipates a **high aggravation of risk for people living with a rare disease in the coming weeks in countries where the level of patients with severe symptoms will soon exceed ICU bed and respiratory aid capacities**. According to our initial analysis, this could be the case in Belgium, France, Iceland, Italy, the Netherlands, Portugal, Spain.

Yann Le Cam, Chief Executive Officer, EURORDIS, "We are hearing shocking stories of violations of the rights of people living with a rare disease and discrimination against them in triage guidelines. This is never acceptable. Equity for rare disease patients also implies that equality may not be enough; rare disease patients are a highly vulnerable population for whom additional special measures must be applied to ensure their health security. How can clinical guidelines in the year 2020 ask for triage based on the value of the person for society, or exclude people with intellectual disabilities?"

He added, "ICU doctors should not be blinded by pre-conceived ideas about rare diseases, nor act on ignorance when knowledge is available. As we have heard from top-level US government officials '*persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities or age*'. For the health and wellbeing of people living with a rare disease, but also as part of efforts to stop the spread of COVID-19 and reduce the need for triage in ICUs, a primary objective should be to prevent vulnerable populations being infected with COVID-19 in the first place. EURORDIS is calling on doctors to practice medicine as an art, using their experience, observations and moral compass to decide how to prioritise patients."

*Precision 02/04/20 : guidelines written by scientific and medical bodies

Our proposals to help healthcare providers during the crisis:

We propose the below special measures to medical bodies, national health authorities, as well as healthcare providers on the ground fighting against COVID-19 to provide optimal care:

- **An immediate revision of all triage guidelines that could lead to the discrimination or de-prioritisation of people living with a rare disease during treatment for COVID-19 in particular in intensive care units.**

Critical care guidelines must be non-discriminatory and should be respectful of fundamental ethical principles and based on “clinical appropriateness and proportionality of the treatments”[†]. They should be aligned with international law, notably the UN Convention on the Rights of Persons with Disabilities (article 11 & 25) and the UNESCO Universal Declaration on Bioethics and Human Rights, as well as disaster medicine ethical guidelines.

- **The immediate adoption of concrete measures/ protocols in the provision of emergency healthcare during the COVID-19 crisis, warranted by the complex needs of rare disease patients, for example:**
 - Lead efforts to ensure **sufficient ICU beds** (including in **temporary hospitals**) and **respiratory aidequipment** are available in order to avoid triage.
 - When a rare disease patient presents with COVID-19 symptoms, the **on-duty ICU doctor should contact the patient’s permanent medical practitioner and/or expert centre** to understand the specific disease history and treatment plan of the patient.
 - For people living with a rare disease, family members play a crucial role in the treatment and care of their loved one. **Carers are experts on the disease and the specific needs of the individual patient and should therefore be permitted to attend the ICU** and support doctors in their relative’s treatment plan and care.
 - **Temporary special hospital wards dedicated to particularly vulnerable rare disease patients affected by COVID-19 should be considered whenever possible** (for example, for patients affected by neuromuscular, pulmonary or immunodeficiency diseases). These should be located in hospitals that already have highly specialised expertise in rare diseases (such as European Reference Network member centres).
 - The use of the **Clinical Patient Management System (CPMS) to expedite exchanges between experts in rare disease European Reference Networks** for those patients affected by COVID-19, in line with the European Commission’s announcement that the model behind the ERN CPMS has inspired a new COVID-19 Clinical Management Support System.
 - People living with a rare disease should be included as a **priority population in preventative measures** to stop the spread of COVID-19. During the containment period, carers of rare disease patients most vulnerable to COVID-19 should be **systematically tested** (or tested on request) with molecular and serological tests. They should receive **masks/ personal protective equipment** as a priority when quantities allow for this beyond priority health/ social care professionals.

[†] Bioethics Committee of the San Marino Republic, Answer to the request for urgent opinion on ethical issues regarding the use of invasive assisted ventilation in patients all age with serious disabilities in relation to Covid-19 pandemic, 16 March 2020: <http://www.sanita.sm/on-line/home/bioetica/comitato-sammарinese-di-bioetica/documents-in-english/documento2116023.html>

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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.