Press release

EURORDIS-Rare Diseases Europe expresses its support for an ECHR case involving cross-border healthcare for a child with a rare disease

Paris, 28 February 2023 **– EURORDIS-Rare Diseases Europe, a non-governmental patient-driven alliance of patient organisations representing more than 1000 rare disease patient organisations in 74 countries, is calling for action in the case of a child with Pierre Robin Sequence, whose case on cross-border healthcare has been pending trial in the domestic court in Lyon since 2019.**

The organisation is asking the European Court of Human Rights to consider the application presented on behalf of Lysiane Pakter to determine whether the prolonged delay in the trial process may amount to a violation of Article 6 of the European Convention on Human Rights.

Article 6 guarantees the right to a fair trial, including the right to have the case heard within a reasonable time. The Court has consistently held that delays in proceedings that are excessive or unjustified can amount to a violation of this right. In particular, the Court has established a number of criteria to assess whether the length of proceedings is excessive, including the complexity of the case, the conduct of the parties, and the conduct of the national authorities.

EURORDIS-Rare Diseases Europe is the voice of 30 million people affected by rare diseases throughout Europe. The organisation acknowledges the challenges faced by families who require access to specialised care, often in different countries to where they live, and understands the importance of cross-border healthcare for patients with rare diseases, who may need to travel to other countries to receive the best available treatment.

The family in question has been fighting for justice in their case since 2017 when Lysiane was born and diagnosed with Pierre Robin Sequence disease. This delay has not only caused unnecessary stress and anxiety for the family but has also had a significant impact on their child's quality of life. EURORDIS-Rare Diseases Europe believes that the prolonged delay in the trial process is unacceptable and could represent a violation of the family's right to a fair trial within a reasonable time.

EURORDIS-Rare Diseases Europe has requested that the European Court of Human Rights take prompt action to ensure that this case is heard without any further delay. We believe it is crucial that the family receives the justice they deserve. This case can serve as a reminder to governments across Europe of the importance of timely and efficient cross-border healthcare for those living with rare diseases.

About the 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.

About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 1,000 rare disease patient organisations from 74 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.

Contact

Julien Poulain
Communications Manager
EURORDIS-Rare Diseases Europe
Julien.poulain@eurordis.org
+33 6 42 98 14 32