

To whom it may concern

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Under protection of HKH  
Crown Princess Mary  
of Denmark

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## **Re.: The case of Lysiane Pakter**

The case of baby girl Lysiane suffering from Pierre Robin Sequence, has come to mine and Rare Diseases Denmark's attention.

Lysiane and her family are caught in a struggle with L'Assurance Maladie, who refuses to authorize a German treatment that is highly specialised and medically proven as a rare disease treatment.

The struggle is a serious one for Lysiane and her family. And it is a devastating example of the struggle that many rare disease patients and families have faced, and continue to face, right here in Europe.

In Rare Diseases Denmark, we strongly believe in the added value of cooperation across borders for rare disease patients and their families. A case like Lysiane's is a violation of the European idea – and most likely also of several formal acts, including the Cross Border Directive (Directive 2011/24/EU on patients' rights in cross-border healthcare).

We strongly urge policy makers, relevant authorities and other relevant decision makers to solve the case of baby girl Lysiane in order to make the best possible treatment available for her, also across borders. It will give hope to Lysiane and her family – and to millions of Europeans living with rare diseases.

On behalf of the national alliance Rare Diseases Denmark,



Lene Jensen, CEO