

M. Nicolas Revel
Directeur Général
Caisse Nationale d'Assurance Maladie

50, Av. Du Prof. André Lemièrè
75986 Paris Cedex20

13 December 2018

Ref: Access to Cross Boarder Healthcare child Lysiane Pakter, EU Directive 2011/24/EU

Monsieur le Directeur Général,

Pro Rare Austria is the Austrian Alliance for Rare Diseases taking part in Health strategies and advocating for the rights of patients with rare diseases in Austria. As member organisation of the European Organisation for Rare Diseases EURORDIS we are involved in European Health Strategies and advocating for the rights of patients with rare diseases on European level.

We are writing to you to ask you to revise your unfounded denial of the baby's right to the most effective treatment provided in Germany.

EURORDIS in their letter (17 November 2017) already pointed out the legal and medical analyses - evidence for safety, efficacy and cost effectiveness of the treatment in Germany included, which we fully endorse.

We raise our voice and ask you to give your approval (S2) and to accept the family's claim to have their rights respected under the EU Directive, thank you!

Nous vous prions d'agréer, Monsieur, l'expression de nos salutations les plus sincères,



Mag. Dominique Sturz
Member of the Executive Committee
Secretary Pro Rare Austria



Dr Rainer Riedl
Member of the Executive Committee
President Pro Rare Austria