

Monsieur le Président de la République
Palais de l'Elysée
55 rue du Faubourg Saint-Honoré
75008 Paris

Brussels, 16 January 2018

Dear President Macron,

Subject: Access to healthcare in France – breach of EU law

We are writing to you on behalf of the European Patients' Forum (EPF), an umbrella organisation representing 74 patient organisations across the EU, to ask for your support in the case of Lysiane Pakter, 9 months old, represented by her parents Mr Philippe Pakter and Ms [REDACTED], to have her right to access cross-border healthcare recognised by the Caisse Primaire d'Assurance Maladie (CPAM) in Lyon.

Equitable access to healthcare is a core patients' right and has been one of EPF's main priorities since the foundation of our organisation. It was in the context of our work on Directive 2011/24/EU on patients' rights in cross-border healthcare that we came in contact with Mr Pakter and Ms [REDACTED]. They have given an excellent overview of the shocking situation they have been faced with after their daughter was diagnosed with the rare Pierre Robin syndrome.¹

Their dispute with CPAM comes down to the following. CPAM rejected the transfer of Lysiane to Tübingen University Hospital in Germany, arguing that the French treatment – which involves connecting the new-born baby to a ventilator machine, and keeping her in an intensive care unit for long-term hospitalisation – is "the same or equally effective" as the highly specialised TPP treatment offered in Tübingen. The latter not only removes the baby's upper airway obstruction but at the same time also corrects its underlying anatomical cause, glossoptosis, without surgery and without long-term hospitalisation. To argue that these treatments are the same, or equally effective, is a surprising claim to say the least. What is even more surprising is the consistent refusal of CPAM to review their assessment, despite the institutional support that Mr Pakter and Ms [REDACTED] have received.

¹ Please see: <http://avantetapres.com/>

We need not repeat the legal and medical analysis of their situation, based on the EU Directive and its transposition into French law, which has been comprehensibly provided by a letter from EPF's member organisation EURORDIS – Rare Disease Europe dated 17 November 2017 and addressed to CPAM. From this analysis it is clear that the right to access care has been breached, and that the assessment of CPAM is not only contrary to the provisions of the EU Directive and the implementing French law, but also to the general spirit of the Directive and the benefits that the sharing of expertise between Member States can have. Especially in the area of rare diseases, this is, of course, of utmost importance.

SOLVIT, a network of national administrations that aims at finding rapid and pragmatic solutions for problems encountered by citizens when EU law is not applied correctly by national authorities, agrees with the legal assessment of Mr Pakter and Ms [REDACTED] and is trying to help them overcome the unnecessary obstacles they are facing.

A prominent Member of the European Parliament, Ms Françoise Grossetête, has also voiced her support to Mr Pakter and Ms [REDACTED]. In her letter of 18 December 2017 to the French Minister of Social Affairs, Health and Women's Rights, she urges CPAM to accept their claim and to have their rights recognised under the Directive. Having been the European Parliament's rapporteur for this legislation, Ms Grossetête has a thorough understanding of the legislation and the rights it grants to citizens.

We wish to add our voice to the above and ask for your kind support in putting an end to this unnecessary struggle of Lysiane's parents to access quality treatment for their daughter, based on an unfounded denial of patient's rights that violates both EU and French law.

Sincerely,

A handwritten signature in blue ink, appearing to read 'N Bedlington', with a long horizontal line extending to the right.

Nicola Bedlington
EPF Secretary General

A handwritten signature in blue ink, appearing to read 'Marco Greco', with a long horizontal line extending to the right.

Marco Greco
EPF President

Annexed:

- 1) Eurordis letter of 17 November 2017
- 2) Letter of Françoise Grossetête of 18 December 2017