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The challenge for family doctors to improve equality in health of patients with rare diseases

Patrick Tabouring

Université du Luxembourg

Corresponding author: Dr Patrick Tabouring, Université Du Luxembourg, Luxembourg, Luxembourg, Luxembourg. E-mail: ameli@pt.lu

Background & Aim: A lot of general practitioners (GP) are less concerned about rare diseases. The aim of our presentation is to familiarize the GP with a specific approach to rare diseases, and to intervene in the inequality of care from which the patients with rare diseases suffer.

Method: in our international working group, the GP's lack of competence when it comes to rare diseases, was discovered with regrettable consequences to the concerned patients.

Therefore, we introduced a training program about rare diseases for the trainees, to evaluate the interest and difficulties with rare diseases, and the possibilities to improve our teaching.

A workshop at a GP congress allowed us to question a group of family doctors.

The later realization of the recommendations issued by these two events made it possible to obtain extremely encouraging results.

Results: The optimal approach to rare diseases by the GP requires the setting-up of an international platform with the collaboration of experienced specialists.

With the help of a distinguished specialist, it was possible for us :

- to create an international working group dedicated to the specific role of the GP when it comes to rare diseases
- to determine an efficient way of the GP's responsabilization concerning rare diseases by the way of adequate teaching
- to assure the incontournable place of family medicine in the care of patients with rare diseases and in the privileged relationship with the patient and their family.

Conclusions: in succession of our work we can affirm the decisive role of the GP in the fight for care quality and equality of patients with rare diseases.