

The need for continuous medical training in the field of rare diseases

This is a supplement of the journal **Medicine and Pharmacy Reports** totally dedicated to rare diseases. Rare diseases represent a group of more than 7000 clinical conditions with a prevalence of less than 1:1500-2000 humans (this definition involves geographical differences and slightly variable acceptance). From this point of view, rare diseases are indeed extremely infrequent each, but not so rare if taken together. Their status of rare disease leads to their status of orphan disease and to the need to be treated by orphan drugs.

The health authorities of most countries have recognized the paramount importance to prevent (whenever possible), to diagnose and to treat rare diseases. As a token of the importance given to such pathological conditions, affecting (severely) few people, it was decided to observe the World Day of Rare Diseases on the 29th of February. The day was specially selected because it occurs every four years only, thus rarely.

However, health care providers and patients celebrate the World Day of Rare Disease yearly in the last week of February. This happened also in 2021. Our center for Gaucher Disease in Romania organized, like every year, a one day symposium on rare diseases. This year it was unfortunately online, but continued the meeting of 2020, which happily could be organized before the lockdown.

This year we decided to publish not only an abstract book but even a volume of proceedings, including most of the papers presented at our meeting from this year. The lectures belonged to Romanian physicians (largely from our

university in Cluj-Napoca) and from neighboring countries Moldova and Bulgaria.

The program of the meeting included this year papers on hereditary amyloidosis, Fabry disease, Gaucher disease, Zenner syndrome, etc. The meeting was supported by Sanofi Genzyme.

Beside this, we added a few other papers from the Postgraduate Course of the European Association of Gastroenterology, Endoscopy and Nutrition (EAGEN) hold in Chisinau, Moldova on 14 November, and organized in a hybrid manner: online and onsite. These papers are dedicated to liver rare conditions and to esophageal motility dysfunctions in eosinophilic esophagitis.

The publication of this proceedings volume is perceived by us as a necessary tool for the continual postgraduate training of healthcare providers in this large and complicated field of rare diseases. Indeed any physician or nurse should be able to indicate screening, to diagnose and to manage rare diseases.

Rare diseases are partly genetic, partly nongenetic. Medical staff should be trained and able to recognize and to prevent them. We hope that our supplement accomplishes our wish to see more doctors and more qualified medical staff to take care of patients with rare diseases.

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