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**'Challenges in Medicines Funding for Rare Diseases**

The ISPOR Spain Chapter organized a Forum presentation during ISPOR Europe 2018 in Barcelona Spain on the "Challenges in Medicines Funding for Rare Diseases." The panel addressed the challenges that arise in health systems to achieve access to drugs for rare diseases, aimed at very small populations of patients.

Josep Torrent, Head of the CatSalut Medicine Area, highlighted the lack of consistency between the data from the clinical studies and the actual clinical practice data; something that, he said, generates that the value of medicines for rare diseases is difficult to measure. In this sense, Marta Traperó, professor and researcher at the International University of Catalonia, said that this identified difficulty to obtain data that generate value makes more complicate to include studies of economic evaluation.

Jordi Martí, (president of Asebio) highlighted the industry's point of view and reviewed the situation of the market of rare diseases globally. In this sense, Martí said that, currently, there are more than 450 drugs in research worldwide for rare diseases, a fact that shows the increase in research efforts in this area.

However, he noted, although there are more and more drugs that are being investigated, that manage to reach the approval process in the regulatory agencies, they face a great barrier which is the lack of access. Thus, he assured that in the current scenario there is a significant delay in the access of this type of medicines in Spain.

From his point of view, the State must ensure that rare diseases are a health priority and, among the measures to be implemented in this regard, he focused on the need to place the patient at the center of all processes, from the investigation until the approval processes. Thus, he urged to encourage research and development of these drugs.