Latin America calls members of congress to legislate on rare diseases

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More than 60 million people are affected by rare diseases in Latin America. People suffering from rare diseases and their families have struggled for years to have access to early and accurate diagnosis, a therapeutic and economic solution for their condition. Some Latin American countries have recognized the right to health and have enacted legislation to assist that population, and moreover, there are countries updating the national regulations to grant access and satisfy the needs of people suffering from rare diseases. However, this is uneven across the Latin American countries. Actually, countries including the right to life and health in the national constitution, they have no regulations or even recognition of the existence of rare diseases. The vision of PERLA 2021 (Rare Disease Program of Latin America) is to have in Latin America and by 2021 promulgated laws for economic coverage and access to diagnosis, medicines, medical devices and health services for people with rare diseases; and to promote the research and development of innovative clinical solutions for those diseases. It is necessary to work in a joint effort across the region where international regulations, practices, and successes are shared, to learn from mistakes, and to create the legal framework to meet the access and innovation needs.

Biography
Fernando Ferrer, MBA, professor of business in college and master programs, is a proven business leader in life science with expertise in global and international strategies in diverse corporate and cultural environments, is member of patient advocacy organizations for rare diseases and cancer, and international trilingual speaker of diverse life science and business related topics. In his presentations, Ferrer covers diverse aspects and solutions related to life sciences in Latin America from the perspectives of its stakeholders, like patients, authorities, and industry.

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