

28th
FEBRUARY
RARE DISEASE DAY

**III INTERNATIONAL
RARE DISEASE FORUM**

**“SHARING INTERNATIONAL BEST
PRACTICES TO CO-CREATE WITH MULTI
STAKEHOLDERS”**



FROM 9 :00 AM TO 12:30 PM



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 **9:00 AM - 12:30 PM**

SCHEDULE

8:50 AM - 9:00 AM	Entrance
9:00 AM - 9:05 AM	Welcome and Moderation Dr. José Josan - Medical Director FEPER
9:05 AM - 9:15 AM	Start Words María Lourdes Rodríguez Heudebert - President Rare Disease Peruvian Federation - FEPER
9:15 AM - 9:35 AM	Advances and challenges in the regulatory policy of orphan medical products in South Korea Dr. Lee Howard - Professor, Department of Clinical Pharmacology and Therapeutics, Seoul National University, Hospital and College of Medicines; Founder and Director, the Center for Convergence Approaches in Drug Development (CCADD)
9:35 AM - 9:55 AM	Participation and promotion of research from civil society in Spain Mr. Juan Carrión Tudela President of the Spanish Federation of Rare Diseases (FEDER)
9:55 AM - 10:15 AM	Newborn screening program: The route and its impact on early diagnosis in Italy Dr. Domenica Taruscio - Former Director of the National Center for Rare Diseases, National Institute of Health (Rome, Italy)
10:15 AM - 10:35 AM	Differentiated mechanisms for the acquisition of orphan drugs in Spain Dr. Jaime Espín, PhD Professor at the Andalusian School of Public Health



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10:35 AM - 10:55 AM	Break
10:55 AM - 11:15 AM	The participation of multi stakeholders for the improvement of people with rare diseases and the innovative project: “Casa Dos Raros” in Brasil Mr. Antoine Daher - President of Febrararas, Casa Hunter, Casa Dos Raras
11:15 AM - 11:35 AM	Social responsibility and interventions of the Rare as One Program for the improvement of people with rare diseases in the United States of America Mrs. Heide Bjornson - Program Manager Rare As One Program - Chan Zuckerberg Initiative - CZI
11:35 AM - 11:55 AM	¿What's next step? A global call to action Durhane Wong- Rieger, Rare Diseases Internacional and CEO of the Canadian Organization of Rare Disorder
11:55 AM - 12:30 PM	Q&A: Co creating with multiple national actors PC. Maruja Crisante - DIGEMID Executive Director of Pharmacovigilance, Access and Use Mr. Luis Vizcarra - MEF General Director of Supply - Ministry of Economy Mrs. Veronica Sifuentes - CEO - EsHoy Mrs. Angela Flores - Executive Director - ALAFARPE Mrs. María Elena Almendáriz - Executive Director - FEPER
12:30 PM	Closure

