


Semana Global 2015 EERR - AgendaFinal ICORD

sesión	moderador	tema	ponentes
Opening (30 min)		Apertura	- John Forman - Virginia Llera - David Peña
Session I:		Global Strategies for Rare Diseases	- John Forman (ICORD President, New Zealand) ICORD's vision and the Yukiwariso Declaration. - Nicola Magrini (WHO, Switzerland) - Ségolène Aymé (IRDiRC Scientific Secretariat, France) IRDiRC update - Presentation from invited speaker
Session II	Virginia Llera (GEISER, Argentina) and David Peña (FEMEXER, Mexico)	Update on The Latin American Rare Diseases Status	-Mikel Arriola (Federal Commission for Protection against Health Risks, COFEPRIS, Mexico), Regulatory facts and needs -Ignacio Burgos (Spain), Progress on regional laws - Alison Joslyn (Shire, Brazil), Challenges and opportunities for rare diseases and orphan drugs in Latin America – an industry perspective -Virginia Llera (GEISER, Argentina), About the rare diseases Latin American day, building a regional identity
Session III		The ethics of resource allocation for Rare Diseases	Keynote lecture Mariana Kruger (Stellenbosch University, South Africa)
Session IV		Inborn errors of metabolism as an example of RD	Presentations and panel discussion - Olaf Bodamer (Harvard University, USA), Medical perspective. A short introduction to metabolic disorders. - Luis Barrera (Javeriana University, Colombia), Research perspective. What research is performed? - Fernando Royo (Genzyme, Spain), Industry perspective - Kelly du Plessis (Rare Disease Society of South Africa, South Africa), Patient perspective - Dra. Esperanza Quiroz /Seguro Popular, Authority perspective - Panel discussion with all presenters. Current challenges, differences around the globe
Session V		Prevention	Invited speakers and Free abstracts - José F Cordero (University of Puerto Rico, Puerto Rico) "Prevention and birth defects" - Domenica Taruscio (Istituto Superiore di Sanità, Italy) "European Recommendations on policies for the primary prevention of congenital anomalies"
Session VI	Emilio Roldan (SLADIMER, Argentina) and Mario Alanis (COFEPRIS, México)	Networking session/Discussion groups session - Moving Research Discoveries to Diagnostic and Treatment Interventions: Opportunities for Collaborative Working Partnerships	Conference participants are welcome to join the discussion group of interest. Discussion groups: 1. Communication: Crowdsourcing and Social Media Role Education of Policy Makers, Regulatory Agencies, Grant Making Organizations, Identify Funding Sources, and Recruiting Patients for Clinical Studies 17:45-19:30 2. Research Infrastructures Natural History Studies, Patient Registries, and Biospecimen Collections 3. Changes in Regulatory Environment Patient, Family, and Physician Risk Acceptance and Risk Tolerance Expedited Review, Breakthrough Therapies, Accelerated Approval, Priority and Fast Track Review 4. Access to Diagnostics and Treatment Interventions Genetic Testing, and Whole Genome, Exome, and Next Generation Sequencing Results Drug Re-Purposing of Existing Products 5. Establishing Research Partnerships Industry, Private Foundations, Academic Researchers, Government Agencies, and Translational Research Programs, Research Conferences 6. The Right to Health International Law, National Constitutions, Human Rights Legislation, Moral Philosophy, and Health System Policy – how these combine and influence the delivery of health care, especially to disadvantaged and vulnerable populations
Session VII	Virginia Llera (GEISER, Argentina)	Patients' voices: International cooperation within patient groups. Why, Who, and How?	- Paloma Tejada (EURORDIS, Rare Disease International, France) - Natasha Bonhomme (Genetic Alliance, USA) - David Peña (FEMEXER, Mexico)
Session VIII		Building the Undiagnosed Diseases Program to a global network	Keynote lecture Cynthia Tift (Undiagnosed Diseases Program, NIH, USA)
Session X		Spreading the word - Incentives for OD development are needed around the world	- Gayatri Rao (Office of Orphan Products Development, FDA, USA) – invited - Fernando Fon Méndez (Mexican Association of Pharma Investigation Industries, AMIIF) - Catalina (CSL Behring, Switzerland)
Session XI	Moderator: Domenica Taruscio (ISS, Italy)	Development and accessibility to international registries and biobanks	- Yaffa Rubinstein (Global Rare Diseases Patient Registry Data Repository, NIH, USA) – Title to be decided - Manuel Posada (Instituto de Salud Carlos III, Spain), Medical ontologies and registering activities. What are their added values?
Session XII		Examples of successful RD collaborations. Progresses in the RD field the last 10 years and futuristic outlooks	- Rashmi Gopal-Srivastava (ORDR, NIH, USA) - The Rare Diseases Clinical Research Network, RDCRN - Antoni Matilla Dueñas (Health Sciences Institute Germans Trias i Pujol, Spain) & The RIBERMOV Latin-American collaboration

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Conclusions and Conference Closing			<ul style="list-style-type: none"> - David Peña - Virginia Llera - John Forman, - Manuel Posada
	 ICORD		
	<hr/> International Conference on Rare Diseases & Orphan Drugs		