



Xth ICORD Meeting, Mexico City, 15-16 Oct 2015

Conference Programme

A decade of discoveries and current challenges in the world of RD and OD

DAY 1- Thursday 15 October

Venue: ISSSTE Buenavista, Mexico City

08:00-08:30	Registration
08:30-09:00	Opening (30 min)
09:00-10:00	<p>Session I: Global Strategies for Rare Diseases Moderator: Simon Day (CTCT, UK)</p> <ul style="list-style-type: none"> - 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 - Paloma Tejada (EURORDIS, Switzerland) – Rare Diseases International
10:00-10:30	Coffee Break
10:30-11:45	<p>Session II: Update on The Latin American Rare Diseases Status Moderators: Virginia Llera (GEISER, Argentina) and David Peña (FEMEXER, Mexico)</p> <ul style="list-style-type: none"> -Mikel Arriola (Federal Commission for Protection against Health Risks, COFEPRIS, Mexico), Regulatory facts and needs -Ignacio Burgos (Ex-senator and Adviser of the health minister, 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
11.45 -12:30	<p>Session III: The ethics of resource allocation for Rare Diseases Moderator: John Forman (ICORD, New Zealand)</p> <p><i>Keynote lecture</i> Mariana Kruger (Stellenbosch University, South Africa)</p>
12.30-13:30	Lunch Break
13:30-15:00	<p>Session IV: Inborn errors of metabolism as an example of RD Moderator: Stephen Groft (NIH, USA)</p> <p>Presentations and panel discussion</p> <ul style="list-style-type: none"> - Stephanie Sacharow (Harvard University, USA), Medical perspective. A short introduction to metabolic disorders.

	<ul style="list-style-type: none"> - Kelly du Plessis (Rare Disease Society of South Africa, South Africa), Patient perspective - Luis Barrera (Javeriana University, Colombia), Research perspective - Fernando Royo (Fundación Genzyme, Spain), Industry perspective - Ezperanza Quiroz (Seguro Popular, Mexico), Authority perspective - Panel discussion with all presenters. Current challenges, differences around the globe.
15:00-15:30	Coffee Break
15:30-16:15	<p>Session V: Prevention Moderator: Manuel Posada (Instituto de Salud Carlos III, Spain)</p> <ul style="list-style-type: none"> - José F Cordero (University of Georgia, USA) – Prevention and birth defects - Domenica Taruscio (Istituto Superiore di Sanità, Italy) - European Recommendations on policies for the primary prevention of congenital anomalies
16:15-17:45	<p>Session VI: Networking session/Discussion groups session - Moving Research Discoveries to Diagnostic and Treatment Interventions: Opportunities for Collaborative Working Partnerships General moderators: Mario Alanis (COFEPRIS, Mexico) and Emilio Roldan (SLADIMER, Argentina)</p> <p>Conference participants are welcome to join the discussion group of interest.</p> <p>Suggested topics for discussion groups:</p> <ol style="list-style-type: none"> 1. Communication: Crowdsourcing and Social Media Role <ul style="list-style-type: none"> • Education of Policy Makers, Regulatory Agencies, Grant Making Organizations, Identify Funding Sources, and Recruiting Patients for Clinical Studies 2. Research Infrastructures <ul style="list-style-type: none"> • Natural History Studies, Patient Registries, and Biospecimen Collections 3. Changes in Regulatory Environment <ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> • Genetic Testing, and Whole Genome, Exome, and Next Generation Sequencing Results • Drug Re-Purposing of Existing Products 5. Establishing Research Partnerships <ul style="list-style-type: none"> • 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
17:45-19:30	ICORD General Assembly (ICORD members only)

DAY 2- Friday 16 October

Venue: ISSSTE Buenavista, Mexico City

08:00-08:30	Registration
08:30-09:30	<p>Session VII: Patients' voices: International cooperation within patient groups. Why, Who and How? Moderator: Virginia Llera (GEISER, Argentina)</p> <ul style="list-style-type: none"> - Gema Chicano (EURORDIS, Spain) - Natasha Bonhomme (Genetic Alliance, USA) - David Peña (FEMEXER, Mexico)
09:30-10:00	Coffee Break
10:00-10:45	<p>Session VIII: Building the Undiagnosed Diseases Program to a global network Moderator: Yaffa Rubinstein (NIH, USA)</p> <p><i>Keynote lecture</i> Cynthia Tifft (Undiagnosed Diseases Program, NIH, USA)</p>
10:45-12:00	Session IX: Poster Session
12:00-13:00	Lunch Break
13:00-14:00	<p>Session X: Spreading the word - Incentives for OD development are needed around the world Moderator: Catarina Edfjäll (CSL Behring, Switzerland)</p> <ul style="list-style-type: none"> - Catarina Edfjäll (CSL Behring, Switzerland), A short update of existing OD incentives in different countries and regions - James Reese (Office of Orphan Products Development, FDA, USA), Updates on recent changes in incentives for rare disease drug development in the United States - Fernando Fon Méndez (Mexican Association of Pharma Investigation Industries, AMIIF)
14.00-15:00	<p>Session XI: Development and accessibility to international registries and biobanks Moderator: Domenica Taruscio (ISS, Italy)</p> <ul style="list-style-type: none"> - Yaffa Rubinstein (NIH, USA), The NIH/NCATS GRDR® Program-Global Rare Diseases Patient Registry Data Repository: Linking patient registries data to bio-specimens data - Manuel Posada (Instituto de Salud Carlos III, Spain), Medical ontologies and registering activities. What are their added values? - Michelle Durborow (The Life Raft Group, USA), Poster presentation: The Global Gist Patient Registry and Tissue Bank
15:00-15:30	Coffee Break
15:30-17:00	<p>Session XII: Examples of successful rare disease collaborations. Progresses in the RD field the last 10 years and futuristic outlooks. Moderators: Désirée Gavhed (Karolinska Institute, Sweden) and Luis Barrera (Javeriana University, Colombia)</p> <ul style="list-style-type: none"> - 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

	<p>RIBERMOV Latin-American collaboration</p> <ul style="list-style-type: none"> - Janine Lewis (GARD, US), The Genetic and Rare Diseases Information Center (GARD): Twelve years of improving access to hard-to-find genetic and/or rare diseases information and resources - Daria Julkowska (French National Research Agency, France), Poster presentation: E-RARE efforts towards patients' involvement in rare diseases research and funding activities
17:00-17:10	The XIth ICORD meeting. ICORD 2016 in Cape Town, South Africa
17.10-17.30	Conclusions and Conference Closing
	Press Conference: David Peña, Virginia Llera, John Forman