

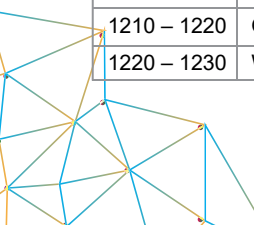


APARDO Conference 2020 (Virtual) Transforming Rare Disease Across the Asia Pacific



Day 1: APAC Rare Disease on the Move

Time SGT	Program	Speaker
0900 - 0905	Welcome	Dr. Ritu Jain, President, APARDO
0905 - 0915	Landscape in APAC region and APARDO activities	
Unique Origins of Rare Disease in APAC region (Opening Panel)		Dr. Durhane Wong-Rieger, Vice President, APARDO; President & CEO, Canadian Organization for Rare Disorders
0915 - 0945	West: Brief Overview of Orphan Drug Acts in USA and European Union (subsidies for R&D and commercialization of orphan drugs to companies) East: Unique origins of rare disease activities in APAC countries (support services and access to treatment for patients) (Panel discussion)	
Fast Forward to Today: Rare Disease Initiatives in APAC Region		Moderator: Dr. Ritu Jain, President, APARDO
0945 - 1000	Regulatory Systems Strengthening for Health Products in Asia-Pacific: Considerations for Rare Diseases	Prof. John Lim, Executive Director, Centre of Regulatory Excellence at Duke-NUS Medical School
1000 - 1015	Orphan Drug Policy in Asia Pacific Countries	Prof. Ian Wong, Head, Department of Pharmacology and Pharmacy, University of Hong Kong
1015 - 1030	How China Copes with Challenges of Rare Disease	Prof. Binyan Sui, Associate Researcher, Division of Health Policy Evaluation and Technology Assessment, China National Health Development and Research Centre
1030 - 1045	20th anniversary of the Rare Disease Act: Taiwan Experiences	Dr. Shio Jean Lin, Chair professor and director of genetic counseling center in Chi Mei Hospital, Tainan, Taiwan
1045 - 1100	Q&A	All speakers
1100 - 1110	Break	
Learning from COVID-19: Addressing Priority Needs across APAC Region		Moderator: Ms. Lisa Foster (Rare Disorders NZ)
1110 - 1210	Panel Discussion <ul style="list-style-type: none"> What has been the Impact of COVID-19 on access to services and support, specifically on organization and delivery of healthcare? How have APAC countries demonstrated resilience to COVID-19 and what are the implications for advancing rare disease policy and actions? How has COVID-19 shone a spotlight on gaps in social, economic, and mental health support and how do we address these? 	Ms. Helen Zhou Shuang, (The Illness Challenge Foundation) Ms. Yukiko Nishimura (NPO ASrid) Ms. Monica Ferrie (Genetic Support Network of Victoria) Ms. Cynthia Magdaraog (Philippine Society of Orphan Disorders) (Healthcare professional, counsellor/social worker, therapist, educator, patients)
1210 - 1220	Q&A	All Speakers
1220 - 1230	Wrap Up	Dr. Ritu Jain, President, APARDO





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Day 2: Global Reference, APAC National Action Plan

Time SGT	Program	Speaker
0900-0910	Welcome Remarks	Dr. Durhane Wong-Rieger, Vice President, APARDO; President & CEO, Canadian Organization for Rare Disorders
Keynotes: Using Global Initiatives to Advance Rare Disease in APAC Region		Moderator: Dr. Durhane Wong-Rieger, Vice President, APARDO; President & CEO, Canadian Organization for Rare Disorders
0910-0930	Collaborative Global Network for Rare Diseases	Mr. Mathew Bolz-Johnson, Programme Director & Healthcare Advisor Rare Diseases International & Eurodis
0930-0950	APEC Action Plan for Rare Diseases and Universal Health Coverage	Dr. Durhane Wong-Rieger, Vice President, APARDO; President & CEO, Canadian Organization for Rare Disorders
0950-1010	Key Findings of the Economist report "Suffering in Silence"	Dr. Ritu Jain, President, APARDO
1010-1030	Global Access to Medicines	Dr. Susanne Weissbäcker, Global Head of Access to Medicines, Takeda
1030-1050	Q&A	All speakers
1050-1100	Break	
Advancing Rare Disease Policy and Actions in APAC Region		Moderator: Ms. Monica Ferrie, CEO, Genetic Support Network of Victoria
1100-1200	Panel Discussion	Mr. Tsang Kin Ping, RDHK, China Hong Kong Ms. Nicole Millis, Rare Voices Australia Ms. Cynthia Magdaraog, Philippine Society for Orphan Disorders Mr. Ekawat Suwataroj, Vice president of Thai Hemophilia Patient Club (THPC), Committee of Thai Rare Disease Foundation (ThaiRDF), Bangkok, Thailand Dr. Duangrudee Wattanasirichaigoon, Chair of Division of Medical Genetics, Department of Pediatrics Dato Hatijah Ayob, Malaysian Rare Disorders Society
1200-1210	Q&A	All Speakers
1210-1220	Wrap Up	Dr. Ritu Jain, President, APARDO

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