



APARDO CONFERENCE THAILAND

25-27
NOVEMBER 2022



Venue: Holiday Inn Hotel Sukhumvit (Bangkok, Thailand)



DAY 0 : Friday, November 25 (5:00PM – 9:00PM ICT)

Time ICT	Program	Speaker(s)
1700 – 1800	APARDO General Meeting	
1800 – 2100	Welcome Reception	

DAY 1: Saturday, November 26 (8:00AM – 7:00PM ICT)

Time ICT	Program	Speaker(s)
0800 – 0830	Registration	
0830 – 0900	Welcome Remarks	Dr. Durhane Wong-Rieger (APARDO & RDI) Dr. Duangrurdee Wattanasirichaigoon (Mahidol University & Thai Rare Disease Foundation) Mr. Anutin Charnvirakul (Thailand Public Health Minister) Ms. Anne-Sophie Chalandon (Sanofi)
0900 – 0930	Session 1 : Rare Disease – A Family Affair	Moderator: Ms. Preeya Singhnarula (Thai Rare Disease Foundation) Ms. Xi Cao 曹茜 (China)
0930 – 1045	Session 2 : Patient-Powered Registries: How to Share and Use Your Data while Maintaining Privacy and Control	Joining us virtually (6:30PM PST): Ms. Sharon Terry (Genetic Alliance) Ms. Dawn Barry (LunaDNA)

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Time ICT	Program	Speaker(s)																
1045 – 1100	Networking Break																	
1100 – 1230	Session 3 : Better Beginnings: Newborn Screening, Genetic Testing, Genomic Sequencing, Genetic Education	<p>Moderator: Ms. Monica Ferrie (Genetic Support Network of Victoria)</p> <p>Dr. Michelle Abadingo (University of the Philippines) Dr. Saumya Shekhar Jamuar (SingHealth Duke-NUS Genomic Medicine Center) Dr. Thong Meow-Keong (University of Malaya, Kuala Lumpur) Dr. Surakameth Mahasirimongkol (Medical Life Science Institute, Department of Medical Science, Ministry of Public Health, Thailand)</p>																
1230 – 1330	Lunch and Networking																	
1330 – 1415	Session 4 : Parade of Asia Pacific Nations: Advances in Rare Disease Policies and Programs Improving Awareness, Education, Diagnosis, Care, Treatment, and Support	<p>Moderator Dr. Durhane Wong-Rieger (APARDO & RDI)</p> <p>Representatives:</p> <table border="1"> <tr> <td>Ms. Monica Ferrie (Australia)</td> <td>Dr. Rachel Yang (China)</td> </tr> <tr> <td>Mr. Tsang Kin Ping (Hong Kong)</td> <td>Mr. Prasanna Kumar Shirol (India)</td> </tr> <tr> <td>Dr. Damayanti Rusli Sjarif (Indonesia)</td> <td>Ms. Nadiah Hanim Abdul Latif (Malaysia)</td> </tr> <tr> <td>Ms. Yukiko Nishimura (Japan)</td> <td>Ms. Michelle Arrowsmith (New Zealand)</td> </tr> <tr> <td>Dr. Ritu Jain (Singapore)</td> <td>Ms. Lisa Foster (New Zealand)</td> </tr> <tr> <td>Ms. Ruth Chen (Taiwan)</td> <td>Dr. Huy Phuoc Do (Vietnam)</td> </tr> <tr> <td>Dr. Michelle Abadingo (Philippines)</td> <td>Dr. Duangrurdee Wattanasirichaigoon (Thailand)</td> </tr> <tr> <td>Ms. Jin-Ah Kim (South Korea)</td> <td></td> </tr> </table>	Ms. Monica Ferrie (Australia)	Dr. Rachel Yang (China)	Mr. Tsang Kin Ping (Hong Kong)	Mr. Prasanna Kumar Shirol (India)	Dr. Damayanti Rusli Sjarif (Indonesia)	Ms. Nadiah Hanim Abdul Latif (Malaysia)	Ms. Yukiko Nishimura (Japan)	Ms. Michelle Arrowsmith (New Zealand)	Dr. Ritu Jain (Singapore)	Ms. Lisa Foster (New Zealand)	Ms. Ruth Chen (Taiwan)	Dr. Huy Phuoc Do (Vietnam)	Dr. Michelle Abadingo (Philippines)	Dr. Duangrurdee Wattanasirichaigoon (Thailand)	Ms. Jin-Ah Kim (South Korea)	
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1415 – 1500	Session 5 : Collaborating for Success Examples from across AP Region	<p>Haemophilia Dr. Apiwat Akarapattananukul Mr. Ekawat Suwantaroj</p> <p>Spinal Muscular Atrophy Ms. Julie Cini (Australia) Dr. Dong Dong (Hong Kong)</p> <p>Lysosomal Storage Diseases Ms. Anne-Sophie Chalandon (Sanofi) Dr. Tan Ee Shien (KKH Singapore) Mr. Manjit Singh (India)</p>																

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Time ICT	Program	Speaker(s)
1500 – 1515	Networking Break	
1515 – 1600	Session 6 : Living Well: Resources and Strategies to Empower Individuals, Families, and Communities	Ms. Yiwei Chen (China) Ms. Nitcha Khunin (Thailand) Ms. Hatijah Ayob (Malaysia) Ms. Ruth Chen (Taiwan) Ms. Nidhi Swarup (Singapore)
1600 – 1645	Session 7 : Leave No One Behind: Leveraging “UN Declaration on Rare Diseases” and UN/WHO Universal Health Coverage to Advocate for Rare Disease Equity and Inclusion	Presenter: Dr. Durhane Wong-Rieger Panellist: Dr. Cherdchai Nopmaneejumruslers (Rare Disease Working Committee, Thai NHSO and Siriraj Hospital, Mahidol University) Ms. Lisa Foster Dr. Rachel Yang Dr. Ritu Jain Ms. Dolores Cvitićanin (RDI)
1645 – 1700	Preparation for Day 2: Collaborating on Rare Disease as Asia-Pacific Region	
1700 – 1900	Reception: Networking with Sponsors and Supporters	

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DAY 2 : Sunday, November 27 (8:30AM – 3:00PM ICT)

Time ICT	Program	Speakers
0830 – 0900	Registration	
0900 – 0930	Key Learnings from Day 1 Introduction to Collaboration and Planning	Moderator: Dr. Durhane Wong-Rieger (APARDO & RDI)
0930 – 1200	<p>Collaboration Roundtables – 3 Rotations of Facilitated Discussion (45 mins/rotation) (8-10 persons/group)</p> <ol style="list-style-type: none"> 1. AP Networks of RD Centres of Excellence and Competence 2. Newborn Screening, Genetic Testing and Genomic Sequencing 3. Patient-Powered Registries for Collecting, Securing, and Using Patient Data 4. AP Regional Strategies for Improving Access to Rare Disease Drugs: Essential Medicines and Advanced or Complex Therapies <p>Rotation 1: 0930 – 1015</p> <ol style="list-style-type: none"> 5. Personalized Therapeutics: Collaborating on Precision Cancer Therapies and Rare and Ultra-rare Drugs <p>Rotation 2: 1030 – 1115</p> <ol style="list-style-type: none"> 6. Equity and Inclusions for Rare Disease: Strategies to address stigma, disability, ethnic/cultural biases, discrimination, gender bias, economic impact, and professional and public ignorance <p>Rotation 3: 1115 – 1200</p> <ol style="list-style-type: none"> 7. Mutual support models for building compassion, competence, confidence, and resilience in individuals and families living with rare conditions 8. WHO Resolution on Rare Diseases 9. Rare Disease Nurses, Genetic Counsellors, and Allied Health Professionals 	
1200 – 1300	Networking Lunch	
1300 – 1430	Report Back: Insights and Actions Potential AP Collaborative Initiatives	
1430 – 1500	Next Steps & Closing Remarks	

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